Position Paper: COVID-19 and Supporting Black Communities at the End of Life

**Prepared by the Diversity Advisory Council of
the National Hospice and Palliative Care Organization**

NHPCO
National Hospice and Palliative
Care Organization

Introduction

There was great excitement and expectation with 2020, new lenses, new visions and new hope for a better and a more enlightened society. These feelings were quickly dashed when COVID-19 took center stage in the global world. As of August 17, 2020 the novel Coronavirus has infected more than 5 million Americans with a death toll of nearly 170,000 of our neighbors, family members and friends.[1] Additionally, the United States is faced with national and international protests over the death of George Floyd, a Black American man killed while in custody of four policemen in Minneapolis on May 25. While most experienced peaceful protests, in some cities and the nation's capital these turned to violence, looting, pepper spray, and arrests. It is against this backdrop that NHPCO's Diversity Advisory Council is putting forth this Position Paper on COVID-19 as it affects hospices with emphasis on the care, treatment and management of diverse populations in the present-day society. In addition, the deaths from COVID-19 to date have impacted the lives of Black people and other diverse groups disproportionately, relative to the general population, nationally and internationally.[2]

The world is seeing severe devastation from the current pandemic. The Diversity Advisory Council in this Position Paper endeavors to help communities at all levels better understand the situation, with emphasis on building trust with the diverse populations relative to patient care and the pain, misery, grief and sorrow caused by this horrible virus.

We must acknowledge the challenges of dying and death: Work at it, work on it and with the affairs of life and living. The work must be done simultaneously, not separately. A better state of affairs will require addressing barriers and/or removing blocks which hamstring society in its impetus to move forward in responding appropriately and effectively. We must not let fear of the past, fear of the present or fear of the future impede our efforts.

This Position Paper will help ethnic communities to put forth and foster a better world in which to live well until you die. As we learn from the past and understand the present, we can move forward in the future with a loving, caring, professional patient/family and community atmosphere. To provide for all people in our global community, it is imperative that we develop strategies related to health, mental health, economics, social care and spirituality.

We cannot, we must not, we shall not and will not lose any ground in relation to what we have achieved in the care of diverse populations in the United States of America.

Building Trust

Perhaps it is time for us to look at the barriers within ourselves as providers versus targeting minority communities wondering why we cannot "get in." In the process of compiling research for this Position Paper, this writer could not help but to entertain the question, "If data has continuously revealed disparities in minority enrollment and the issue researched to the extent it has been— why are we not seeing significant improvement in national data?" The institution of hospice and palliative care may in fact need to change itself, its views, its practices, and its mentality.

According to a 2016 Journal of Palliative Medicine article, *Racially Associated Disparities in Hospice and Palliative Care Access: Acknowledging the Facts While Addressing the Opportunities to Improve*, African-American hospice utilization does not correlate with the population's excessive mortality rate from most causes of death—including hospice eligible diagnoses.[3] Other researchers

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[1] https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html
[2] Data source: COVID-19 case-level data reported by state and territorial jurisdictions. Case-level data include about 80% of total reported cases. Numbers are unadjusted rate ratios. https://www.cdc.gov/coronavirus/2019-ncov/downloads/covid-data/hospitalization-death-by-race-ethnicity.pdf
[3] Payne, Richard. "Racially Associated Disparities in Hospice and Palliative Care Access: Acknowledging the Facts While Addressing the Opportunities to Improve." *Journal of Palliative Medicine*, vol. 19, no. 2, 2016, pp. 131–133., doi:10.1089/jpm.2015.0475.

suggest that social determinants are more likely to change before the more resistant problem of health disparities.[4] Ultimately, organizations should entertain innovative minority engagement initiatives that add genuine value to communities rather than investing in "Diversity, Inclusion and Equity" solely for capitalization and incentivization. Hospice and palliative care providers would do well to educate themselves on the psyche of Black, Indigenous, and People of Color (BIPOC) that has been shaped by systemic racism, socioeconomic inequities, and disparities in health care education.

"Ought I to trust or not?"

Inclusion is accomplished not by telling communities what they should do, but through establishing trusting relationships. (NHPCO Inclusion and Access Toolkit)

Of all the ingredients of human connection, "trust" is at the core. There are keywords within our vocabulary that have phenomenon elements to them, and "trust" is one of those words. For something to be a phenomenon, it must be an observable fact or event. The sheer nature of "trust" fits into this category every time. *Trust* is defined as *"a situation characterized by the following aspects: One party (trustor) is willing to rely on the actions of another party (trustee); the situation is directed (in the current position) and the future hopes."[5]* The word spreads across multiple subject matters, and health and health care treatment is one that carries an immense weight of responsibility. Trust is the consideration of one person or group of people promising to fulfill a task or duty on behalf of another. Trust is the gateway to a host of emotional feelings that can have both positive and negative outcomes—that challenge the gatekeeper. When you look at the nature of trust you must be willing to investigate the whole and not just the personal adornment of your safety.

One's space of fragility must become challenged to the point that you are willing to have your privilege broken, damaged, and become vulnerable for the greater cause of all and not some who share cultural genetics and ideology of a select. But many seek to keep their created privilege intact and avoid placing themselves in any state of vulnerability. The title of this writing comes at the hands of the epistemology of trust which asks the question, "Ought I to trust or not?" The epistemology is the study of knowledge, and we must ask what we know about trust and what do we need to know about it.

In the investigation of "trust," we must seek to bring the focus of it into view with the hopes that it has promise. Annette Baier states the difference between trust and reliance by saying that **trust can be betrayed**, **whilst reliance can only be disappointed**.[6] The basis of her statement comes at the heels of Sissela Bok, who said in her writings, *"Whatever matters to human beings, trust is the atmosphere in which it thrives."[7]* If the philosophy of trust is a matter of being betrayed and a matter of thriving from the hopes of another being willing to contribute to the needs of the human being's plight, then what has happened?

The social vantage point of trust is, or at least is supposed to be, that we are all, in some form, in a position to contribute to the social setting of the advancing of each other. But there are barriers that have and continue to hinder this advancement among all people without prejudice and hate. Some of the leading barriers are greed, selfishness, and pride, and it is with just these three that mistrust continues to be cultivated by many lives. Barbara Misztal cites in her book *that trust "makes social life predictable, it creates a sense of community, and it makes it easier for people to work together*."[8] And it is by these claims that we have experienced a disconnect around the subject of trust. Can you have trust without truth?

Let us investigate each one of Barbara Misztal's claims.

- ***It makes social life predictable.*** Her first statement has a quality of hope which says with trust comes a space of "social life predictability" meaning that one could predict the nature of another on the basis of trust in them or the lack of trust in them. It is difficult to imagine that this level of trust is available, especially in the circumstances of meeting the basic needs of food, clothes, shelter, and health care access and treatment.

[4] Satcher, David, et al. "What If We Were Equal? A Comparison Of The Black-White Mortality Gap In 1960 And 2000." *Health Affairs*, 2005, www.healthaffairs.org/doi/full/10.1377/hlthaff.24.2.459.

[5] Definition of Trust. **https://en.wikipedia.org/wiki/Trust_(social_science)**

[6] Baier, Annette. "Trust and Antitrust." *Ethics*, vol. 96, no. 2, 1986, pp. 231–260. *JSTOR*, www.jstor.org/stable/2381376. Accessed 18 Aug. 2020.

[7] Bok, Sissela. Lying: Moral Choice in Public and Private Life. New York: Pantheon, 1978. 326. Print.

[8] Snijders, Chris, and Barbara A. Misztal. "Book Review." *American Journal of Sociology*, vol. 102, no. 6, 1997, pp. 1724–1725. *JSTOR*, www.jstor.org/stable/10.1086/231133. Accessed 18 Aug. 2020.

- ***It creates a sense of community.*** The language of this statement has an air of hope in the sense that people have come to trust those within their community on the basis of desired hopes or positive interactions with each other and that a system of correction is in place for mishaps.
- ***It makes it easier for people to work together.*** The nature of trust is also valid in that a community that has come to a place of trustworthiness has desire and a plan to work together.

The unfortunate nature of trust is when the dominant community sets the stage for what and who is to be trusted. This is concerning because the liberty of others is then not valid nor valued. The psychology of trust is the expectation that others will do what they said they would do without or with limited biases. The exclamation of our psychological behavior and how we feel about self and others is often times viewed as a state of discomfort due to many who identify as racial and ethnic minority groups lacking the feelings of hope and security—knowing that our needs have the possibility of being met in fragments, rather than whole. To eliminate all forms of biases is unrealistic; every person has formulated biases throughout their life. What is important is to eliminate the negative impact our biases have on the decisions we make, especially when providing care to others.

To put forth the sheer nature of equitable hope and its ability to offer fair and impartial opportunity is a dream we seek to bring into reality. So how do we add in a connection of trust to end-of-life care in this difficult environment? The most cited concern is maneuvering through or within the health care system before needing palliative and/or hospice care. If the access, treatment, resources, and care is lacking in the beginning, trust is less likely to be there in the moment of end-of-life. The number of cited cases that speak to the mistreatment of minority and underrepresented families is too numerous to just pick one.

The blame for the cause of this mistrust is not one person or one group, but it is the nature of the system that has been created. Insurance rates and coverage, a profit-over-people philosophy, and access depending on geographical location are just a few contributing elements. Not too long ago, doctors made house calls to address sickness and treatment. With the modernization of technology and science, the scope of discovery has gotten more advanced, but fair treatment in health care has not been able to keep the pace.

Some health agencies have felt that returning to the "House Call" model may be the needed answer to supporting sickness and terminal illness. The goal must be to serve and support everyone. One of the great threats to minorities is the inability to receive proper care, in fear of being unheard, misunderstood, judged, misdiagnosed, or worse, feeling that your culture is being targeted for a research study. Patients desire high quality, unbiased health care—that is not dependent on the color of their skin nor their ZIP code.

Though the Affordable Care Act has expanded access to health care to those who are traditionally underserved, opportunities still exist to increase the quality of care. Hospice and palliative care providers must not dismiss the prior journey of treatment along the way. Nancy Krieger, Ph.D., a professor at Harvard School of Public Health, has linked an association between Jim Crow laws as a contributing factor to more lethal breast cancer among U.S. Black women.[9] Many discriminatory acts were addressed within the laws of government in the 1960s, but we must still must address and endure the effects of discrimination in our health care system.

Various examples of mistreatment in the health of minorities and underserved communities continue to impact the decisions made by patients who identify as such when posed with health care decisions. It is important to note that African American men have been the targeted group to test a vaccine to treat syphilis only to be allowed to suffer from another untreated health condition at the hands of science.[10] As we live through a time when the push for a vaccine is a top priority for scientists throughout the world, how many people will die of COVID-19 because they don't trust the vaccine that will ultimately be pushed to prevent it?

How can the health care system and clinicians overcome existing barriers in trust to ensure patients' and families' physical and cultural needs are met? The answer to this question is seemingly simple to answer but difficult to execute. To address this one must reference the statement made at the beginning that **"Inclusion is accomplished not by telling communities what they should do, but through establishing trusting relationships."** It is from that we must start the dialog.

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[9] Krieger N, Jahn JL, Waterman PD, Chen JT. Breast Cancer Estrogen Receptor Status According to Biological Generation: US Black and White Women Born 1915-1979. *Am J Epidemiol*. 2018;187(5):960-970. doi:10.1093/aje/kwx312
[10] https://www.cdc.gov/tuskegee/faq.htm

There are additional factors to consider that affect health and health care, such as the systematic structural racism and the inequalities in access to housing, education, employment, and justice. The health disparities we face challenge us on how we enter this life, maintain a sense of quality of life and how we transition into the eternal place. *Isaiah 26:3-4; You will keep him in perfect peace, whose mind is stayed on You Because he trusts in You. Trust in the Lord forever, For in Yah, the Lord, is everlasting strength.* It is in that trusting of a higher being that we can discover answers to these barriers.

What are some tangible ways to overcome these barriers and build trust?

- Have a health and health care advocate, someone who is in a neutral place but has the influence and authority to see things through.
- Build a framework around treatment and quality of life for elders.
- Identify implicit biases and reflect on the impact they have on decisions made related to patient care.
- Have a clear and precise plan of care and dialog with physician and patient about all options.
- Schedule time for relationship building. If there are patients who are traditionally underserved, plan to spend more time discussing options, providing education, and building trust. Doing this on the front end will prove to be beneficial to both the patient and clinician later.
- Advocate for equitable laws related to health care. The Hospice Action Network and NHPCO advocate annually for policies that impact the Medicare Hospice Benefit and all are welcome to join.

If at any length and hope of achievement, we can get to the place Dr. Bernice C. Harper speaks of which is to *"Go ye, therefore and learn from each patient, each family, each culture, and each community"* to accomplish our dreams of good health and good health care, even at the end of life.

The Impact of Mental Distress on Chronic Disease in the Black Community

In the early days of COVID-19, the White House Task Force announced the importance of coupling humanities with science in desperation to tackle our national health emergency. Several weeks later, the U.S. watched Black America's suffering with its own eyes. "I can't breathe" became the anthem of an oppressed people and Black Lives Matter sparked a national dialogue. Two national emergencies happening simultaneously—with health care and injustice at its center.

An unprecedented pandemic and social unrest made us witnesses to a "New Kind of Grief." This national emergency inspired grief compounded by pre-existing mental stressors sparked by the unceasing emotional tragedy of racism, economic marginalization and poor health in Black communities. An activist in Sacramento told *The Washington Post*, "I'm exhausted. All these things build up, and they make your soul feel such unrest. And then you add that to all the lives that nobody got justice for."[11] The correlation between mental distress and chronic illness amongst Blacks begins with the infrastructure of our cities, states, and nation. David R. Williams, Professor of Public Health and African-American studies at Harvard University, writes that Black communities have been living with a pandemic of chronic stress—surviving on low household incomes, living in sub-standard housing compounded by violence and pollution long before COVID-19.[12] **According to Williams, people exceed their ability to cope with stress when it is persistent and routine.** Physical responses include high blood pressure, heart disease, obesity, and diabetes, among other health concerns—illnesses that disproportionately affect Black communities.[13]

Dedication to communal health begs a starting point. Systemically racist and exclusivist institutions are now called to fulfill rhetoric of "Diversity, Inclusion and Equity." The institution of hospice and palliative care has a unique opportunity to assign meaning and action to rhetoric. Beyond medical care, organizations can drive societal health by understanding the psyche of marginalized communities, which requires learning about the plight of a people before asking for their business. For instance, it is imperative for

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[11] Holly Bailey, Annie Gowen. "'It's a Blue-Soaked Anger': Amid Protests, African Americans Feel a Private Grief." *The Washington Post*, WP Company, 31 May 2020, www.washingtonpost.com/national/its-a-blue-soaked-anger-amid-protests-african-americans-feel-a-private-grief/2020/05/31/8a31fe6e-a360-11ea-bb20-ebf0921f3bbd_story.html.

[12] Williams, David R. "Opinion | Stress Was Already Killing Black Americans. Covid-19 Is Making It Worse." *The Washington Post*, WP Company, 13 May 2020, www.washingtonpost.com/opinions/2020/05/13/stress-was-already-killing-black-americans-covid-19-is-making-it-worse/.

[13] Ibid.

hospice and palliative care providers to understand the development of Black communities and the impact systemic racism via real estate has on socioeconomic determinants of health.

Redlining

The economics behind redlining was an intentional effort to alienate Black people from the mainstream community. The system of redlining was instituted by mortgage lenders and property owners who outlined specific areas within a city on a color-blocked rating scale. Maps of neighborhoods outlined the highest concentration of blacks in red. Red represents "hazardous" and credit risks—a rating system intentionally designed to set the course for generational poverty, poor education and illness.[14]

Hospice and palliative care providers can work towards diversity, inclusion and equity by doing a map analysis of their cities and service areas and pose the following questions:

- Is this organization participating in redlining by not servicing economically disadvantaged neighborhoods?
- Do we identify economically disadvantaged neighborhoods as "unsafe" in order to not serve them?
- How can my organization add value to impoverished communities?
- Which staff have innate cultural competency skills for initiative implementation?

Economics of Redlining, Education and Health Care Segregation

Commitment to addressing racial and socioeconomic health inequities requires overstepping redlines and learning about dynamics beyond research and data gathering—we must ask minority communities what they need from us and be willing to meet these needs. To develop diversity, inclusion and equity strategies, hospice and palliative care organizations need to provide education regarding health system comprehension and navigation, disease processes, and establishing plans to die at home for residents of Black redlined neighborhoods—where access to education has been historically and systematically withheld.

With the suburban community comes the suburban education system. The redlined inner-city/urban community comes with a "hope to become adequately educated" system. For generations, Black, Indigenous, and People of Color (BIPOC) raised children whose education lacked exposure to complicated English language spoken in mainstream society. These children became parents within a perpetual cycle; thus, lacking the ability to be higher education role models.[15] Redlining, inaccessible education, and health disparities have deep systematic, racist connections. Mapped red lines distinguishing Black, "hazardous" and "high credit risk" communities also carved out segregated health systems.

Health care system segregation continues to influence chronic disease susceptibility and mortality rates among Blacks. The economics driving education and health segregation suggests that there are two health systems—one for those who know how the system works and its benefits, and one for those who *decide to trust* and hope to benefit.

Hospice and palliative care providers are encouraged to position themselves in the gap between these redlined delivery systems by addressing disparities in health care education.

Organizations can:

- Conduct an analysis of the education system within redlined communities
- Identify age group(s) that may benefit from early chronic disease education
- Consider investing in a community health education campaign
- Be innovative about multi-generational engagement
- Collaborate with unlikely community health equity stakeholders

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[14] Fortson, Jori. "Rating Health After Redlining." *Public Health Post*, 24 Jan. 2020, www.publichealthpost.org/research/rating-health-after-redlining/.
[15] Commentary • By Richard Rothstein • November 12, Richard Rothstein. "The Racial Achievement Gap, Segregated Schools, and Segregated Neighborhoods – A Constitutional Insult." *Economic Policy Institute*, Race and Social Problems, 12 Nov. 2014, www.epi.org/publication/the-racial-achievement-gap-segregated-schools-and-segregated-neighborhoods-a-constitutional-insult/.

- Develop sustainable programs
- Normalize hospice and palliative care services by establishing a presence across the health care continuum
- Engage with or including faith leaders in dialogue

While hospice and palliative care organizations cannot single-handedly renew society, there are opportunities to earn and establish trust with a community of persons who have no reason to trust and to educate where education has been withheld. "Black Health" has been a longstanding conversation. Service providers can reinvent what it means to preserve quality of life and develop initiatives to be health system educators and *trusted* service providers.

It is this section's assertion that hospice and palliative care participation throughout the health care continuum via health education would establish sustainable relationships with BIPOC. Provider initiatives that add value to communities of color in addition to capitalization efforts will have also earned opportunities to become preferred providers by BIPOC for both existing and future generations. Should the hospice and palliative care industry miss opportunities to utilize education as a guide to leading disparate communities out of racial, socioeconomic and health inequities, we will continue to see data that suggests we aren't trying hard enough to serve the totality of our communities.

A New Kind of Grief: How COVID-19 Has Affected the Grieving Process of Disenfranchised Communities

Grief is defined as a feeling of deep sorrow, and per the Kubler-Ross model, the 5 stages of grief consist of *Denial*, *Anger*, *Bargaining*, *Depression* and *Acceptance*.[16] Since these stages are considered universal and experienced by people across many cultures, and not necessarily in the same order, during this pandemic the experience of grief has become more enhanced. Adjusting to loss of personal freedoms, resources, jobs, schools, social groups, health, and death simultaneously has pushed communities of color that are already dealing with racial and health disparities into finding new ways to cope and mourn.

Grief expert David Kessler provides his perspective about how people can work to process feelings during this pandemic and explains how it relates to the stages of grief.

- Denial: *This virus won't affect us.*
- Anger: *You're making me stay home and taking away my activities.*
- Bargaining: *Okay, if I social distance for two weeks everything will be better, right?*
- Sadness: *I don't know when this will end.*
- Acceptance: *This is happening; I have to figure out how to proceed.*

Acceptance is where the power lies and where we find a sense of control. "*I can wash my hands. I can keep a safe distance. I can learn how to work virtually*." It's interesting that David Kessler used this as an example for Acceptance because a disproportionately high share of Black and Hispanic workers cannot telecommute from home, according to a report by the Economic Policy Institute based on federal labor data.[17] People of color often live in urban areas, live in multi-generational homes, and work jobs that are deemed as "essential." Each of these factors impact how communities of color manage their grief while dealing with the loss due to COVID-19.

Now that we have defined grief, let's look at the types of grief for a better understanding of how communities are being greatly affected.

- Anticipatory grief: *Feeling of grief for an impending death.*
- Sudden grief: *Unexpected and devastated nature of the experience.*
- Complicated grief: *Grief that is prolonged and dramatically interferes with the ability to function.*

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[16] The five stages of grief. https://www.psycom.net/depression.central.grief.html
[17] Not everyone can work from home. https://www.epi.org/blog/black-and-hispanic-workers-are-much-less-likely-to-be-able-to-work-from-home/ (March 19, 2020)

- Ambiguous grief: *Loss that occurs without closure or clear understanding.*
- Disenfranchised grief: *Grief that is not acknowledged by society.*
- Collective grief: *Grief felt by a collective group such as a community.*
- Post-traumatic grief: *A medically defined condition applied to people who are suffering challenging thoughts and reactions following a stressful event.*

At any given time, communities are experiencing these types of grief on both a macro and micro level. From witnessing the tragic deaths and loss of members in the Black community on social media as a nation to seeing how grief is affecting us personally in our own households.

While COVID-19 has disrupted many communal traditions, sudden and ambiguous grief have forced a new norm upon many cultures in traditions regarding death of loved ones, be it a repast, funeral mass, graveside service and/or *shiva*.[18] Now we are seeing how communities that have experienced greater COVID deaths will have to process their grieving and the PTSD that may result after this has concluded. In some Native American communities, many face the challenges of jurisdiction, time and distance when retrieving the body of their loves ones to have them buried on their native soil in keeping tradition to their mortuary customs. The Native American community believes that the whole person should be brought back to their native grounds, be it body part from an amputee, or even the placenta from birthing a baby. There can be resistance when seeking medical service outside of the tribal communities because of the low number of health professionals available to the community, now the patient and/or family is out of that tribe's jurisdiction and the federal government rules are different. These traditions are not always honored outside of the Native American community and so more barriers are present when trying to collect the bodies of their loved ones, especially during these times.

In communities where places of worship are sanctuaries of emotional and spiritual refuge, these groups have experienced tragic numbers of deaths due to COVID-19. Although there was some resistance regarding social distance recommendations early on, the number of deaths that occurred in faith-based communities has led to increase usage of phone prayers lines and virtual service resources. For all communities, new social distancing guidelines has added heightened distress and complicated grieving processes leading to extended, complicated grief and healing. The inability to complete these rituals and traditions have left many families and friends wondering if they have truly honored the legacy of their loved one, creating feelings of ambiguous grief, guilt, and a lack of closure. These changes have left many with feelings of deprivation because of social distance guidelines and not being able to be comforted, or to be the comforter, without those social interactions of touches and hugs. Since grief looks different for everyone, it is common to experience feelings of extreme sadness, anger and emotional disconnection or numbness.[19] Grief can manifest with physical symptoms such as changes in digestion, forgetfulness, shortness of breath, exhaustion, aches and pains that you didn't notice before and a change in your normal sleeping habits.

This new grief was greatly enhanced with anyone admitted to the hospitals, assisted living facilities, independent living facilities, and nursing home communities. With the Associated Press reporting that one in four deaths in a nursing home were related to COVID-19, visitations with friends and family members were prevented, and often times home care and hospice staff were limited from serving their hospice patients for fear of spreading COVID-19.[20] Residents quarantined for up to 14 days experienced various changes in their routine and loss of interaction with their loved ones. This has had a great impact on their physical and mental health, leading to additional feelings of loss and separation.

Face-to-face visits required by Medicare and Medicaid were now done via tablets and phones, and this became the new normal. Electronic devices have become a tether line between patients and families trying to keep some form of normalcy. Many means have been promoted in helping to get grief and mental health help to those who normally would not seek out those services, such as telehealth, tele psych services, Zoom, Facebook apps, and phone calls. Providers such as End of Life Doulas saw an increase in requests for online training from professionals and caregivers alike. It is recommended by the APA and the Mental Health Association of America to continue those practices after the pandemic has passed and restrictions have lifted. Continual follow-up and monitoring will be important because this pandemic will have a long impact on the mental health and grief in the community

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[18] A seven day formal mourning period for immediate family, following burial of a Jewish person.
[19] Weir, K. (2020, April 1) Grief and COVID 19: Mourning our bygone lives. Retrieved from **https://www.apa.org/news/apa/2020/04/grief-covid-19**
[20] Nursing homes represent more than 1 in 4 COVID-19 deaths. https://apnews.com/7f79f4e427cf45523d6270f01e5f33ea (June 18, 2020)

further down the line.

Conclusion

At the onset of the year 2020, many celebrated a year of new vision. At the time, very few anticipated that the world would be challenged with a global pandemic that would greatly impact the economy and education systems and become the cause of death for nearly 170,000 people in the United States. Although 2020 has yet to unfold as many planned and hoped for, the impact of COVID-19 on Black communities has become undeniably clear.

When one becomes a clinician, a commitment is made to respect the basic principles of medical ethics: autonomy, justice, non-maleficence, and beneficence. According to Stanford University, beneficence "demands that health care providers develop and maintain skills and knowledge, continually update training, consider individual circumstances of all patients, and strive for net benefit."[21] Building and maintaining trust between a clinician and patient is mutually beneficial and imperative when considering how to best care for the whole person.

NHPCO's Diversity Advisory Council is a diverse group of hospice and palliative care professionals, dedicated to increasing access to care for those who are traditionally underserved. Like many health care workers, this group sought ways to positively impact change in health care disparities as the data was released related to COVID-19 hospitalizations and deaths. Hospice and palliative care are about peace, respect, honor, and hope. Knowing that so many have died in solitude, away from their families, and at higher rates due to the social determinants of health, contradicts what we represent as hospice professionals.

The existing social determinants of health and inequitable access to high quality care did not develop overnight and will not be resolved immediately. But steps must be taken to ensure that all patient needs are being met. Take time to build trust; invest time and energy into every ZIP code within your service area; be humble enough to know that there's always more to learn and be open to it; and remember the oath taken when the decision was made to become a clinician. There are always opportunities for personal growth, but we must seek them. Hospice and palliative care were created to provide a personalized plan of care that supports the physical, psychosocial, and spiritual needs of patients and families. In essence, our care is about meeting patients exactly where they are, no matter who they are.

Each person is uniquely created, but we all are born and we all will die. No one's skin color, religion, income bracket, ZIP code, or any other differing factor should determine the quality of care received at the end of life. In the words of Representative John Lewis,

"If you see something that is not right, not fair, not just, you have a moral obligation to do something about it."

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[21] Stanford University.
https://web.stanford.edu/class/siw198q/websites/reprotech/New%20Ways%20of%20Making%20Babies/EthicVoc.htm#:~:text=Ideally%2C%20for%20a%20medical%20practice,beneficence%2C%20and%20non%2Dmaleficence.

History of the Diversity Advisory Council

Everything in the world has a beginning, a middle and an end. Thus, the current Diversity Advisory Council of 2020 was appointed by Edo Banach, JD, President and CEO of the National Hospice and Palliative Care Organization (NHPCO).

The Diversity Advisory Council has a historical foundation upon which to build this Position Paper on the Coronavirus (COVID-19). In 1986, the National Hospice Organization (NHO), which later became the National Hospice and Palliative Care Organization (NHPCO), under the Presidency of John Mahoney and the Board of Directors at the time, established the Task Force on Access to Hospice Care by Minority Groups. Dr. Bernice Catherine Harper was appointed Chair, which was tantamount to saying, "No good deed goes unpunished."

The Task Force on Access to Hospice Care by Minority Groups lasted for 10 years. It set the stage for a variety of programs with the impetus on access and utilization by all minority groups. Activities included town hall meetings, workshops, position papers, reviewing manuals, guidelines and evidenced based practices. These activities gave credence to what became known as the Great Hospice Commission. "Go ye, therefore and learn from each patient, each family, each culture, and each community. Thereby, setting the stage for future generations in the development and utilization of hospice care."[22]

The Task Force also represented an understanding on behalf of NHPCO to assist hospice programs across the country in their outreach plans to serve the entire community. Hospice surveys revealed that more attention needed to be given to the ethnic needs of terminally ill patients and families from all minority backgrounds.

A Regional Conference was held in 1991 entitled "Improving Access to Hospice Care for People of Color." In 1996 there was a national meeting entitled "Meeting the Needs of the Terminally Ill Persons of Color and Their Families." An important support document designed to assist hospices in their efforts to improve access by minority groups was the National Hospice Organization's Resolution on Access passed by the membership in May 1992. The Resolution stated in part: "Resolved that the National Hospice Organization rededicate its efforts to reach the goal of universal access to hospice care for the terminally ill individuals in the United States." This gave impetus to the fact that NHPCO was taking the necessary steps to make hospice care available to all Americans.

This Position Paper was written by NHPCO's Diversity and Advisory Council. Members of that Council include:

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[22] Caring for Our Own with Respect, Dignity, and Love: The Hospice Way. Arlington, VA, The National Hospice & Palliative Care Organization, 1994.

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