



Hospice Through the DEI Lens

.....
A Research Study Identifying Barriers to
Hospice Care in Underserved Communities



NHPCO

Leading Person-Centered Care

nhpco.org



Background

The Medicare hospice benefit was established in 1982 to cover services for patients who have received a prognosis of six months or less to live, as well as their families. This benefit was established to support any hospice-eligible patient without limitation. On average, 1.5 million individuals utilize the Medicare hospice benefit annually, yet **significant disparities exist in hospice utilization among certain populations.**

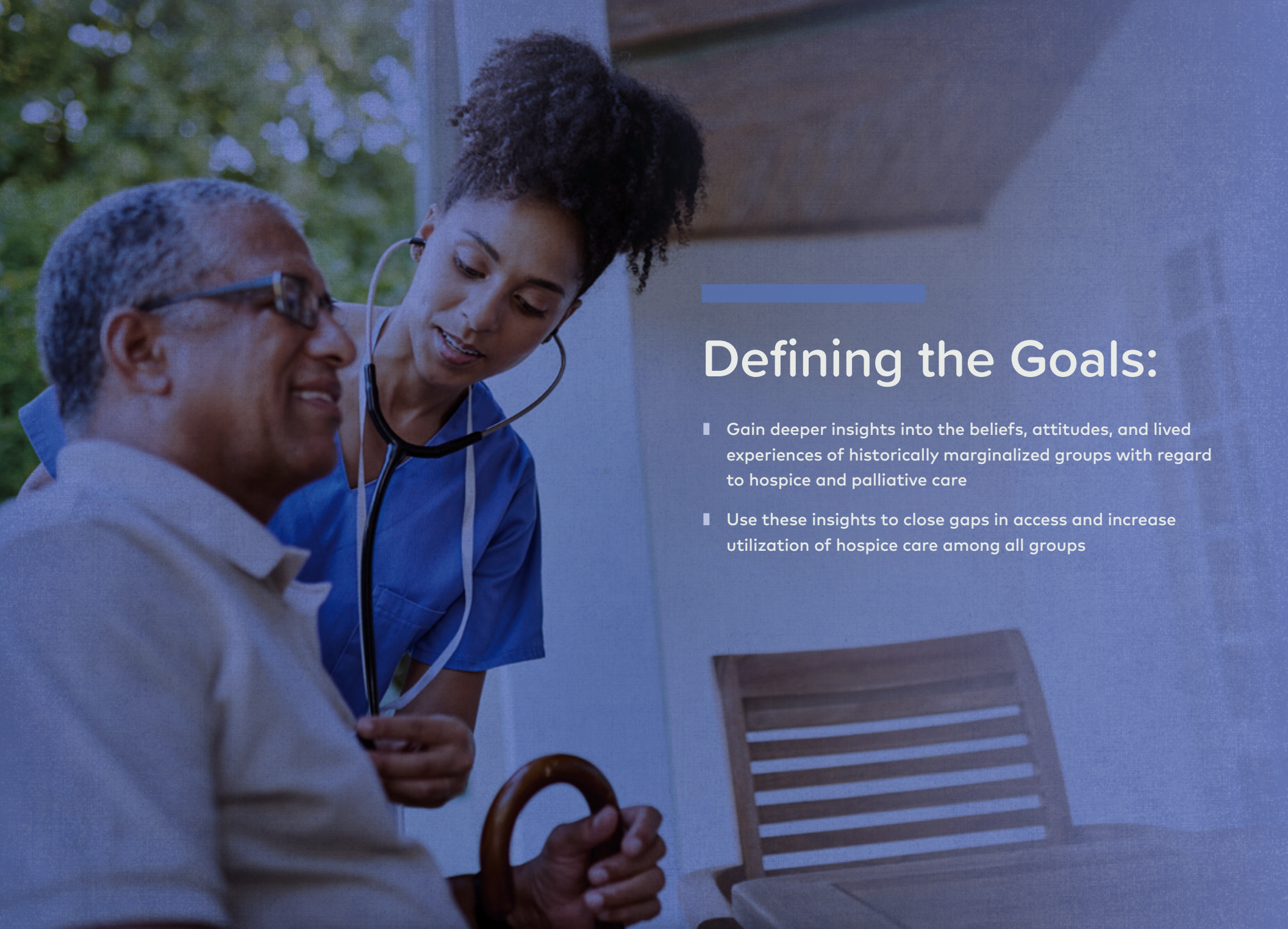
The National Hospice and Palliative Care Organization (NHPCO) Diversity Advisory Council is committed to understanding hospice through the lens of diversity, equity, and inclusion (DEI) and to **breaking down barriers to accessing hospice and palliative care** through knowledge sharing, data collection, and collaborative discussion. We are grateful for our partnership with Transcend Strategy Group on this research project.

The following data are focused on three specific populations within the United States: African American/Black, Hispanic/Latino, and LGBTQ+. We plan to expand our research to include additional populations in 2023. Our hope is that this research will inspire stronger community partnerships, increased education, and a greater understanding of patient and community needs at the end of life.



Identifying the Problem:

- Ongoing health inequities continue to impact the Black, Hispanic, and LGBTQ+ communities
- This includes disparities in hospice utilization among patients from these underserved groups



Defining the Goals:

- Gain deeper insights into the beliefs, attitudes, and lived experiences of historically marginalized groups with regard to hospice and palliative care
- Use these insights to close gaps in access and increase utilization of hospice care among all groups



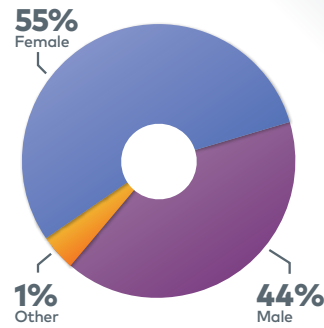
Setting the Strategy:

- NHPCO conducted a nationwide survey (n=1,200) of adults (21+) who experienced the death of a loved one or have been involved with healthcare/life care decisions for someone with a serious illness within the past 3-4 years. Participants identified as:
 - Black (n=400)
 - Hispanic/Latino (n=400)
 - White (n=200)
 - LGBTQ (n=200)
- The research was analyzed, and four key domains emerged for Understanding Hospice Through the DEI Lens. **Language, Information, Finances, and Experience.**

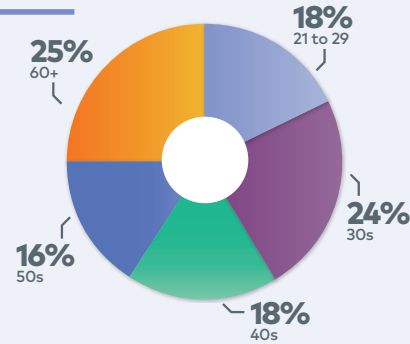
Total Respondent Profile

(Sample of 1,200)

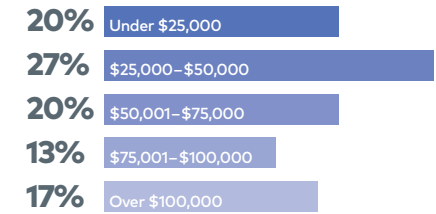
Gender



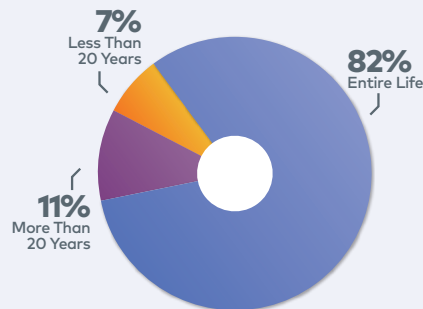
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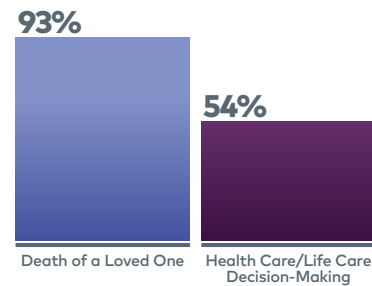
Income



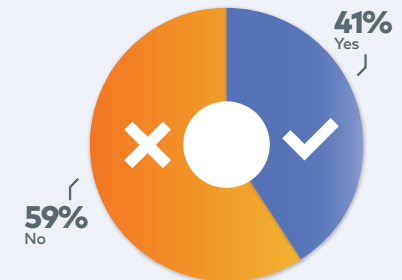
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Experience with (% answering "yes")



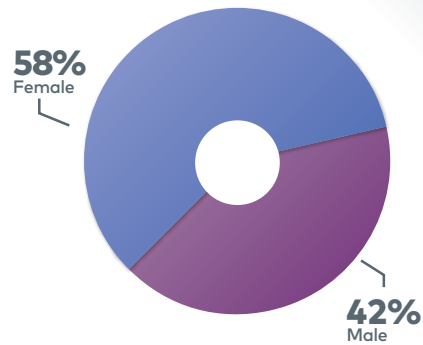
Heard of Palliative Care



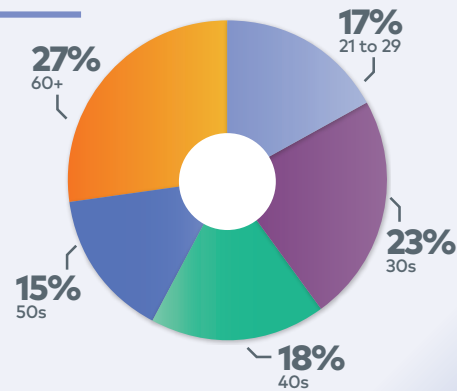
African American/Black Demographic Profile

(Sample of 400)

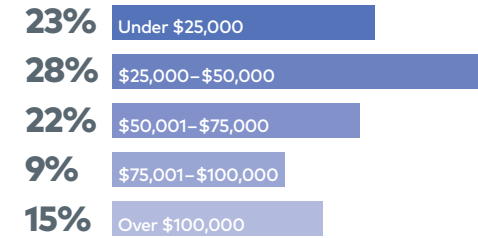
Gender



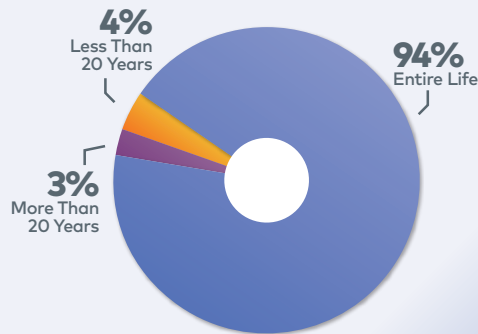
Age



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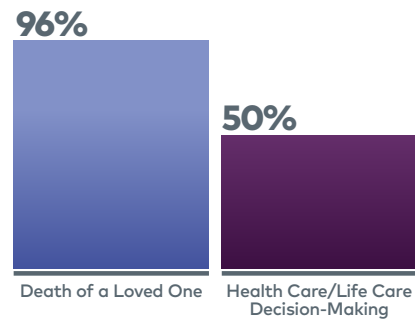


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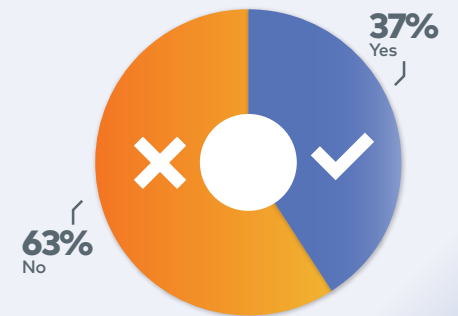


Experience with

(% answering "yes")



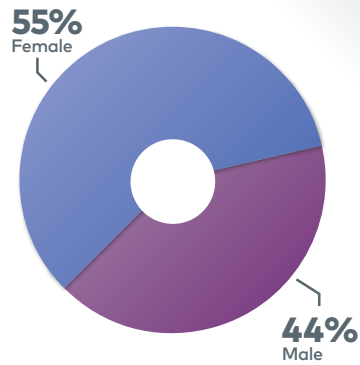
Heard of Palliative Care



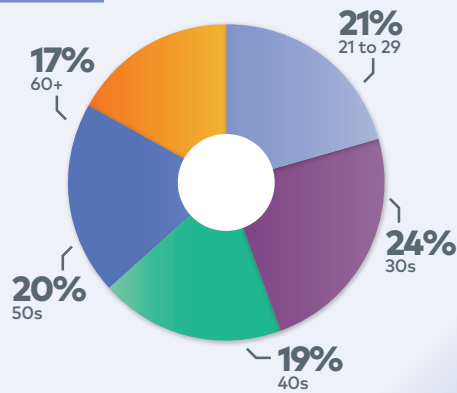
Hispanic/Latino Demographic Segment Profile

(Sample of 400)

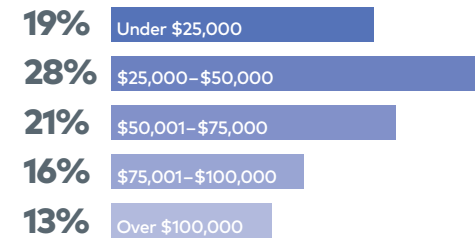
Gender



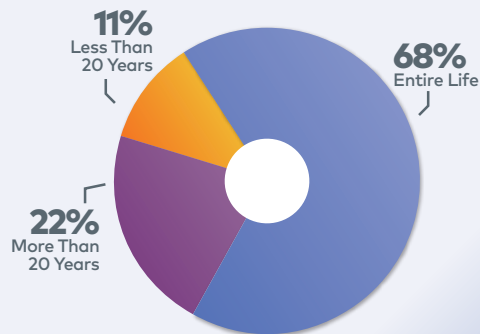
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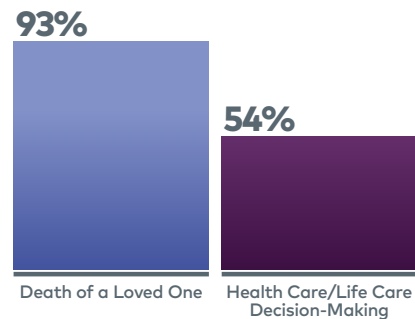
Income



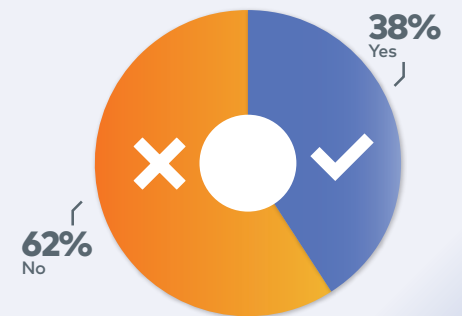
Lived in the U.S.



Experience with (% answering "yes")



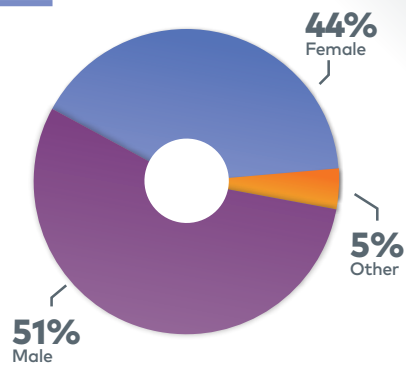
Heard of Palliative Care



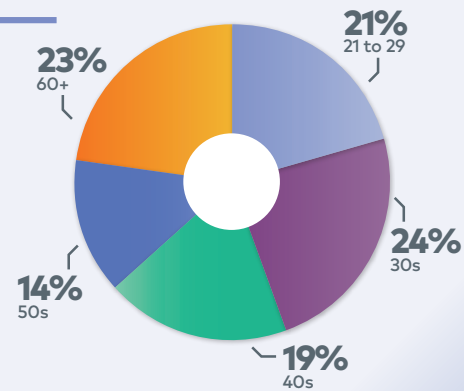
LGBTQ+ Demographic Segment Profile

(Sample of 200)

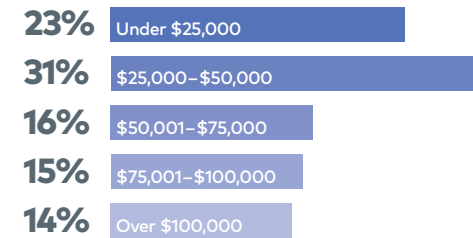
Gender



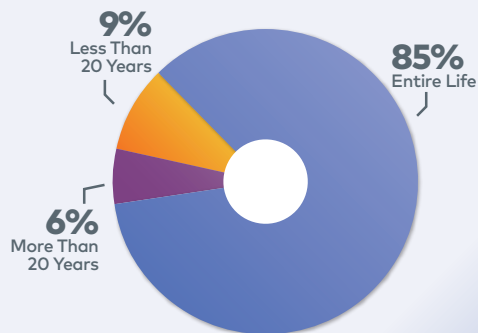
Age



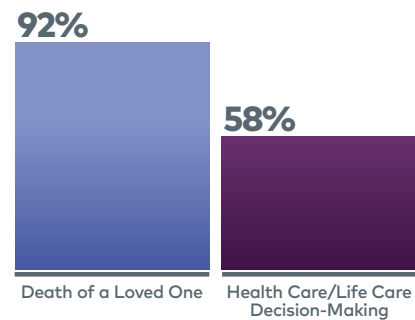
Income



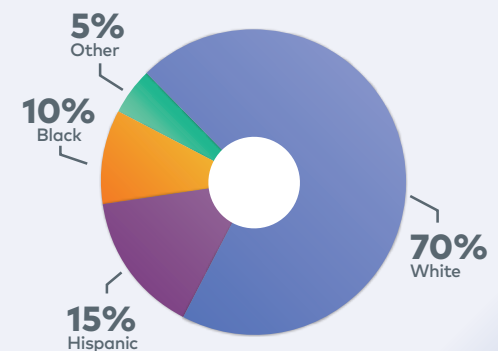
Lived in the U.S.



Experience with (% answering "yes")



Racial Identity





Four Key Domains for Understanding Hospice Through the DEI Lens



Location



Information



Finances



Experience



A closer look at the domains of LIFE



Information: WHAT key pieces of knowledge will be shared?

Key concerns:

- Many have uncertainties about what the “right” time is to transition to hospice care
- Different demographic groups vary in their most trusted source of information related to hospice



Location: WHERE will the care be delivered?

Key concerns:

- Many are unaware that hospice care can be provided in home
- Many would be unwilling to put their loved one in facility-based hospice





A closer look at the domains of LIFE (cont.)



Experience: WHAT key pieces of knowledge will be shared?

Key concerns:

- Differences in culture, language, and sexual orientation are viewed as potential barriers to receiving respectful, non-judgmental treatment by hospice workers
- A religious/spiritual component to hospice is important: many would seek it out, others would specifically avoid it



Finances: WHO will be responsible the cost of care?

Key concerns:

- Many are unaware that Medicare covers the cost of hospice
- Navigating health insurance processes can be confusing and frustrating





Looking Deeper

Different groups often had meaningfully different beliefs and experiences regarding hospice and palliative care.



Black



Hispanic



White



LGBTQ+



Key Findings and Takeaways:

Hospice and the Black Community



Hospice and Religion: Black Community

Compared to White respondents, Black respondents are significantly more likely **(59% vs 50%) to want a religious or spiritual component to hospice.**

59% vs 50%

If a hospice organization has spiritual/religious components and resources, these should be played up to those patients and families for whom spirituality is important.



We pray, and we want you to pray with us. If we have a pastor come in, we will want you to participate in that with us



Hospice and Identity: Black Community

Compared to White respondents, Black respondents are significantly more likely **(21% vs 11%) to feel more comfortable with hospice workers who are the same ethnicity as their loved one.**

21% vs 11%

- This desire for cultural similarity further underscores the need for diversity at all levels of hospice staff and leadership.
- Prioritize your organization's commitment to culturally proficient care and give concrete examples of what you're doing in both internal and external communications.
- Provide ongoing education to your staff to address cultural issues important to your community.



A person who looks like me, when they look at my family, will be able to understand a little bit differently versus someone who doesn't have the same cultural experiences.



Key Findings and Takeaways:

Hospice and the Hispanic/Latino Community



Hospice and Language: Hispanic Community

Language can be a significant barrier for non-native English Speakers. More than half (**52%**) of **Hispanic respondents** said they would need hospice workers who spoke their loved one's language in order to feel comfortable.



- Written materials (both print and digital) should be available in a variety of languages. Even if a patient and/or their loved ones can read English, offering materials in their native language, and in a culturally appropriate way, demonstrates a commitment to honoring their culture.
- Diversity of language is a key component to overall diversity. Hospice organizations should ensure language diversity that mirrors that of their patient population.
- Develop best practices for engaging with interpreters to ensure all communications maintain the qualities of care and compassion.



As long as they speak Spanish, that's basically my only requirement. If they're human, and they speak Spanish, I'm good with that.

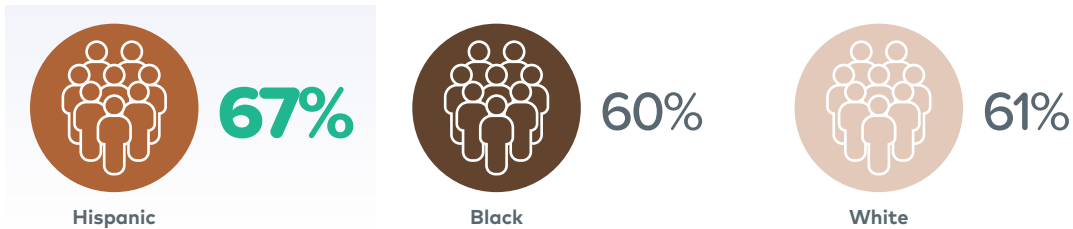




Hospice and Information: Hispanic Community

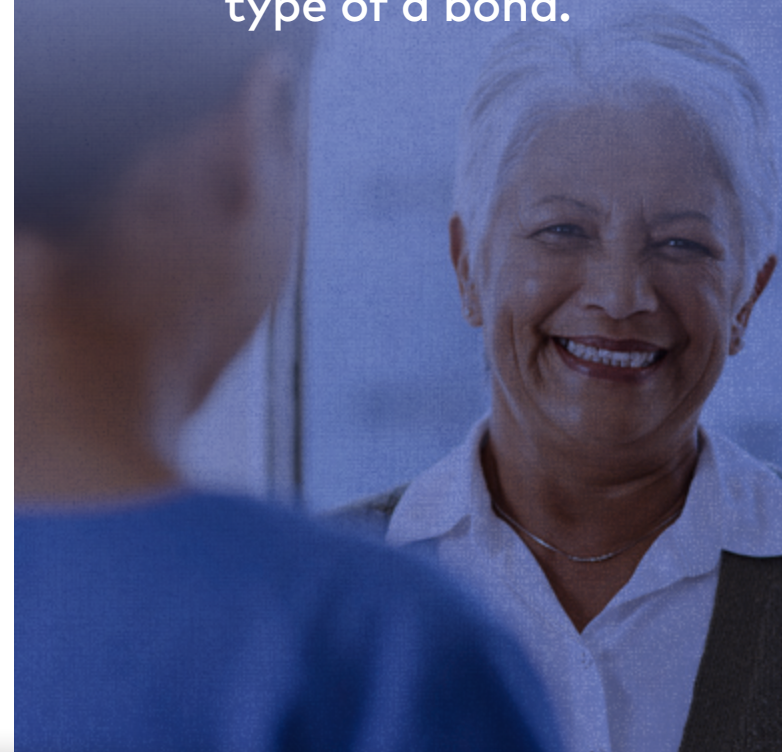
Compared to other groups, Hispanics appear to have a greater knowledge gap around hospice and palliative care services.

67% of Hispanic participants want to know what services are offered.



- Develop materials targeted to the Hispanic community that help them gain a better understanding of how hospice works. People need complex information in written form so they can read it after they leave the doctor's office; they are often too overwhelmed by the situation or intimidated by the power dynamics between provider and patient to ask questions in real time.
- Do more to make services known and allow the family to personalize the experience.
- Provide clear education around the dying process to patients and families. Take the time to answer all questions and use non-medical language when explaining what to expect.

I would feel if you're non-Hispanic, but you spoke Spanish and could communicate, I would have some type of a bond.





Issues Affecting the Black & Hispanic Communities Similarly



My idea of hospice is that it's a facility, it's a place you go to, or you submit patients to and they spend their last few chapters in that place, but they're taken care of.



You know that your loved one will be comfortable, but you have to decide whether they'll be comfortable away or at home.



Hospice Location: Black & Hispanic Communities

A sizable minority of **Black (22%) and Hispanic (25%) respondents are either unaware or unsure of whether hospice can be provided in the home or a healthcare facility**

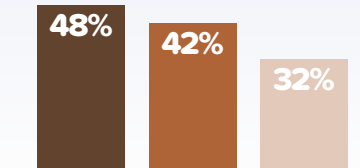
Compared to White respondents, Black and Hispanic respondents are significantly more likely **(32% vs 42% vs 48%) to not use hospice if it were only offered in a facility (and not at home).**

22%
BLACK



25%
HISPANIC

unaware or unsure of whether hospice can be provided in the home or a healthcare facility



Black Hispanic White
not use hospice if it were only offered in a facility



- Black and Hispanic caregivers should be assured of the many options available for hospice care. Hospice can be provided at the patient's residence, an in-patient facility, a nursing home, or wherever the patient calls home.
- Get to know patients' and their families' expectations and fears. Assure patients and their families that hospice care can be customized to meet their individual needs.



It's important to highlight when something is going to be financially covered—that it is not going to come out of pocket. An assumption people make is that something like hospice care happening in your home has to be exorbitant.



Hospice & Cost: Black & Hispanic Communities

Compared to **White (52%)** respondents, **Black (39%)** and **Hispanic (41%)** respondents are less likely to be aware that hospice is a benefit covered by Medicare.



52%



39%



41%



- Black and Hispanic caregivers should be advised early on of the hospice benefits offered by Medicare, as well as the typical costs of hospice for those with Medicaid or private insurance.
- Ensure understanding that hospice is an at-home option that is covered by their benefits.
- Clearly explain how the Medicare hospice benefit works. This can be on the hospice organization's website AND printed collateral.
- Be sure to highlight the value of hospice care.



Key Findings and Takeaways:

Hospice and the LGBTQ+ Community



The moment they find out you're gay, or the moment they find out that you're not what they think is normal, they totally treat you differently.



Hospice & Respect: LGBTQ+ Community

Nearly 1/3 of LGBTQ+ respondents doubt or are unsure that hospice would respect their sexuality.

Many respondents would be willing to believe that a hospice company was accepting of their lifestyle if that hospice had a member of the LGBTQ+ community in a decision-making role.



1/3

LGBTQ+ respondents doubt or are unsure that hospice would respect their sexuality.

- Prospective LGBTQ+ clients need reassurance that they will be treated with respect.
- Consistently collect patient demographic information, including gender identity and preferred pronouns.



The majority are basically underwritten by one religious organization or another. Many of my LGBTQ peers don't ascribe to religion so you're putting them in an awkward situation.



Hospice & Religion: LGBTQ+ Community

The LGBTQ+ community has the lowest interest in a spiritual or religious component to hospice care for themselves or loved ones.

They are significantly less likely (39%) to want a spiritual or religious component to hospice care compared to other survey respondents.



less likely (39%) to want a spiritual or religious component to hospice care

- Clarify optional offerings for spiritual and religious care. Openly share that the role of the chaplain/spiritual support team is to support the patient's needs, not to advocate for religious conversion.
- Ask residents/patients if they have any cultural or religious preferences prior to establishing care. Do not assume all patients seek the same type of care.



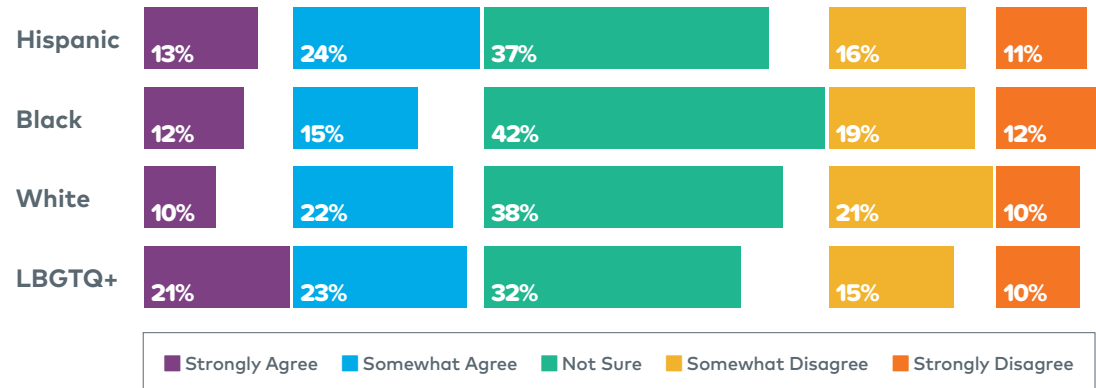
Key Insights



Doctors often wait too long to talk about hospice, making it a crisis decision to use it.

Community partnerships continue to be very important, however, patients and loved ones trust their doctors more than anyone else to refer them to a specific hospice.

Almost 1/2 of LGBTQ respondents believe doctors wait too long to talk about hospice, making it a crisis decision. A significant number of Hispanic respondents feel the same.

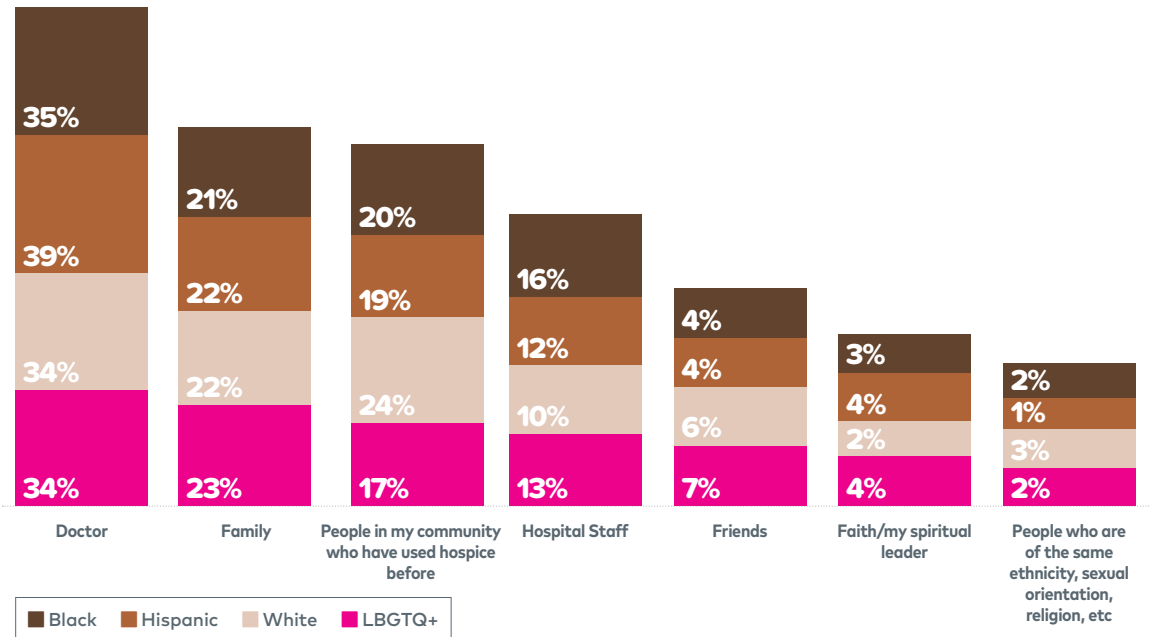


- Offer in-services to healthcare providers on how to have conversations about hospice with patients and families.
- Share this data with your referral partners.



Who would you trust to recommend a specific hospice to you?

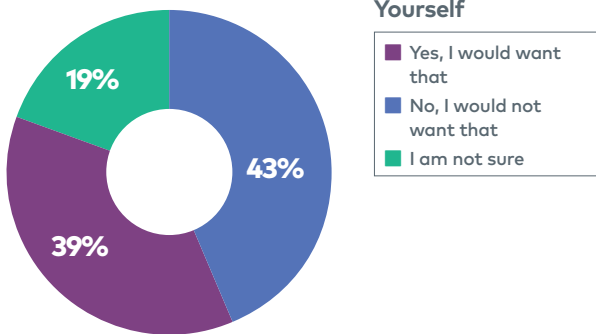
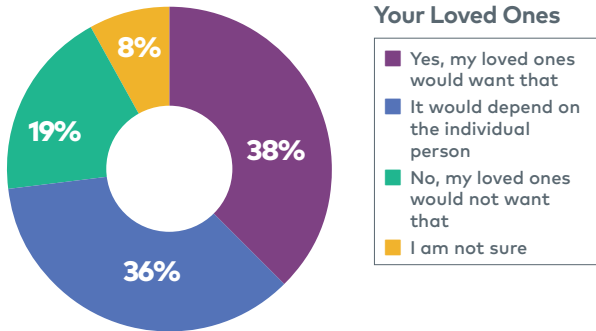
Who would you trust to recommend a specific hospice to you?



Would you want a spiritual or religious component to the hospice care for your loved one? For you?

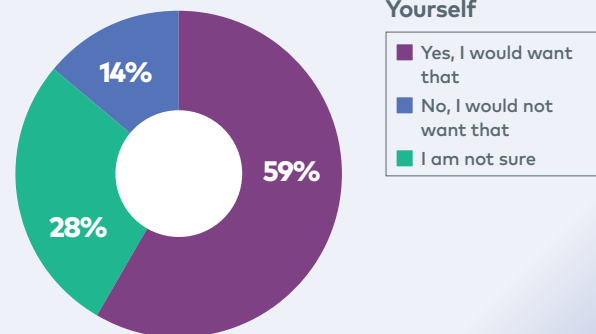
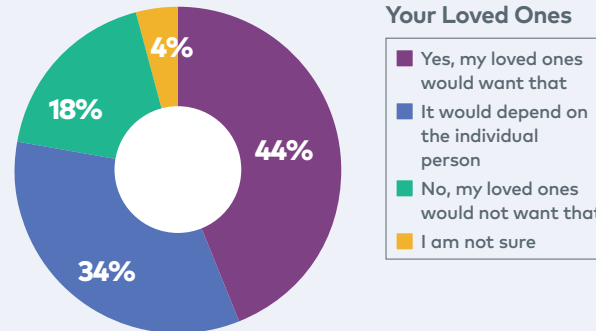
LGBTQ+

Segment has the lowest interest in a spiritual or religious component to hospice care for themselves or loved ones



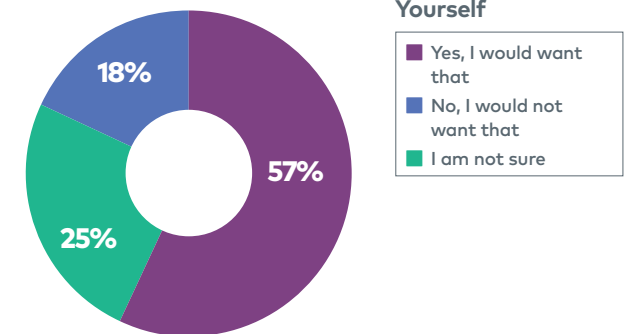
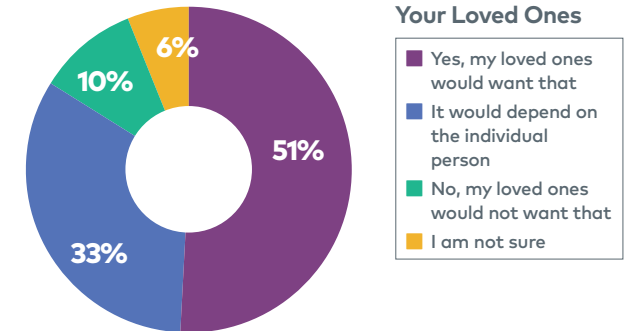
Black

More than half would want a spiritual or religious component to hospice care for themselves



Hispanic

About half want a spiritual or religious component for themselves or loved ones



Additional Resources

www.nhpco.org/diversity

To help facilitate a dialogue on hospice care with members of underserved communities, NHPCO has developed the following community outreach resources:



Black and African-American Outreach Guide



Chinese American Outreach Guide



Latino Outreach Guide



LGBTQ+ Resource Guide