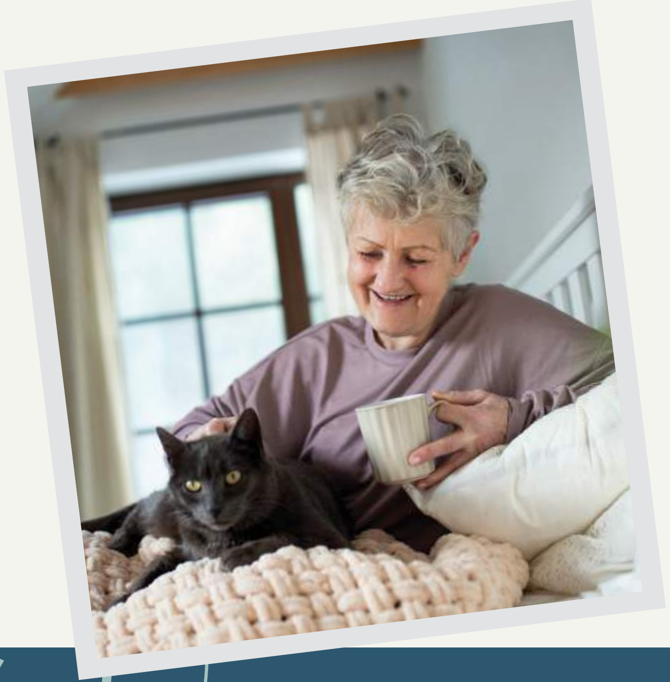
Rural American Hospice Insights

Understanding the Needs of the Rural Family Caregiver

National Alliance
for Care at Home

Transcend™
Strategy Group

Healthcare Challenges Facing Rural Communities



Rural family hospice caregivers represent a critical yet often overlooked group in the healthcare landscape. These individuals, typically family members providing care to terminally-ill loved ones at home, face unique challenges that differ from those encountered by caregivers in urban settings. The geographic isolation, limited access to healthcare resources, and potential financial strain of rural communities can exacerbate the emotional, physical, and psychological burdens placed on these caregivers. Despite their essential role in providing compassionate support at the end of life, the needs of rural family hospice caregivers remain insufficiently understood and under-researched.

The Diversity Advisory Council (DAC) of the National Alliance for Care at Home (the Alliance) wholeheartedly recognizes that underserved populations are not limited to the basis of gender, race, or religion. DAC members seek to explore the challenges faced by this particular underserved population, emphasizing the importance of tailored support services to address their distinct needs. By focusing on rural family caregivers, we aim to contribute to a more comprehensive understanding of the gaps in hospice care and advocate for more equitable resources and support.

Healthcare Challenges Facing Rural Communities

As with other marginalized groups, the healthcare quality of rural patients and caregivers is shaped by a number of factors that constitute *Social Determinants of Health*. **These factors impacting their care can include:**[1]

- Limited access to services due to remote distance and travel needs for services
- Low health literacy in medical terminology and patient symptom management
- Limited English-language proficiency
- Perceived clinician racial and ethnic discrimination
- Financial vulnerabilities affecting health care coverage
- Underdeveloped infrastructure

These barriers adversely affected decision-making, communication with clinicians, and the management of patient symptoms. Family caregivers reported experiencing emotional distress due to the challenges in managing patients' symptoms and the lack of opportunities for respite.

Reference: 1. Patano, A., Wyatt, G., & Lehto, R. (2024). Palliative and End-of-Life Family Caregiving in Rural Areas: A Scoping Review of Social Determinants of Health and Emotional Well-Being. *Journal of palliative medicine*, 10.1089/jpm.2023.0566. Advance online publication. https://doi.org/10.1089/jpm.2023.0566

Healthcare Challenges Facing Rural Communities

Study Background:

In an effort to better understand the needs and beliefs of caregivers living in rural America, the Alliance (formerly the National Hospice and Palliative Care Organization) commissioned a research study among 400 caregivers living throughout rural America.

What, exactly, qualifies as rural?

- Rural encompasses all population, housing, and territory not included within an urban area.
- Urban refers to densely developed territories that have populations of 50,000 or more.

Given the often remote nature of rural communities relative to urban healthcare hubs, providing quality hospice and home care to the rural community often requires overcoming multiple logistical and psychosocial hurdles.

Total Respondent Profile: **Overview**

Respondents spanned a diverse cross-section of age, income, education, and ethnicity. This underscores the intersectional nature of their lived experience, with geography/rural identity being one of several factors influencing their needs and beliefs.

Intersectionality **is defined as:**

The understanding that human experience is jointly shaped by multiple social positions (e.g. race, gender, socioeconomic status), and cannot be adequately defined by considering social positions independently.

For added understanding of how race, ethnicity, and sexual orientation can shape patients' and caregivers' views on hospice, download this resource.

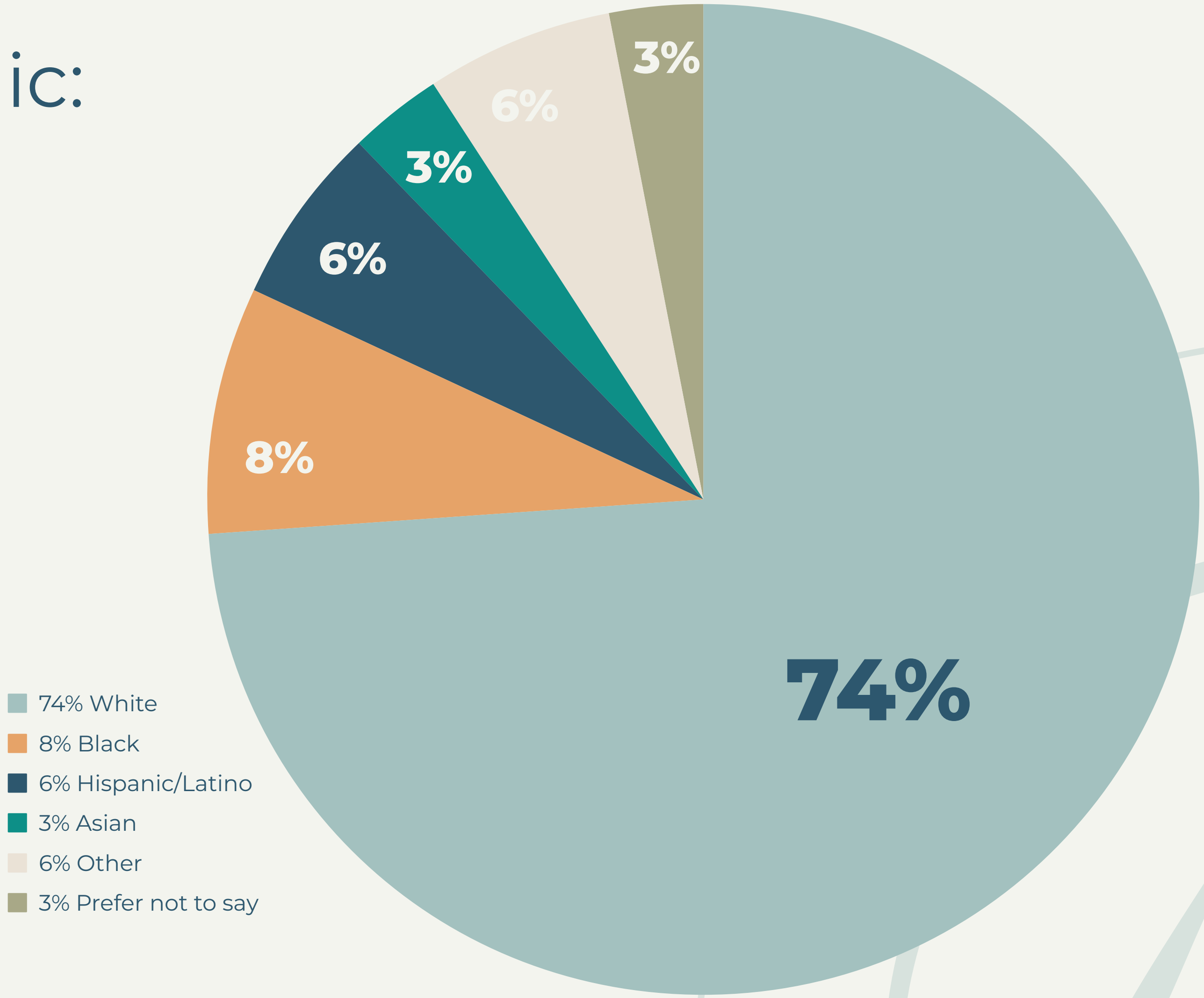
Respondent Demographic:
Race/Ethnicity

74%

of respondents identified as White.

Key Finding:

While **74% of respondents** identified as White, the racial breakdown of the research cohort was roughly comparable to that of the greater rural American population.



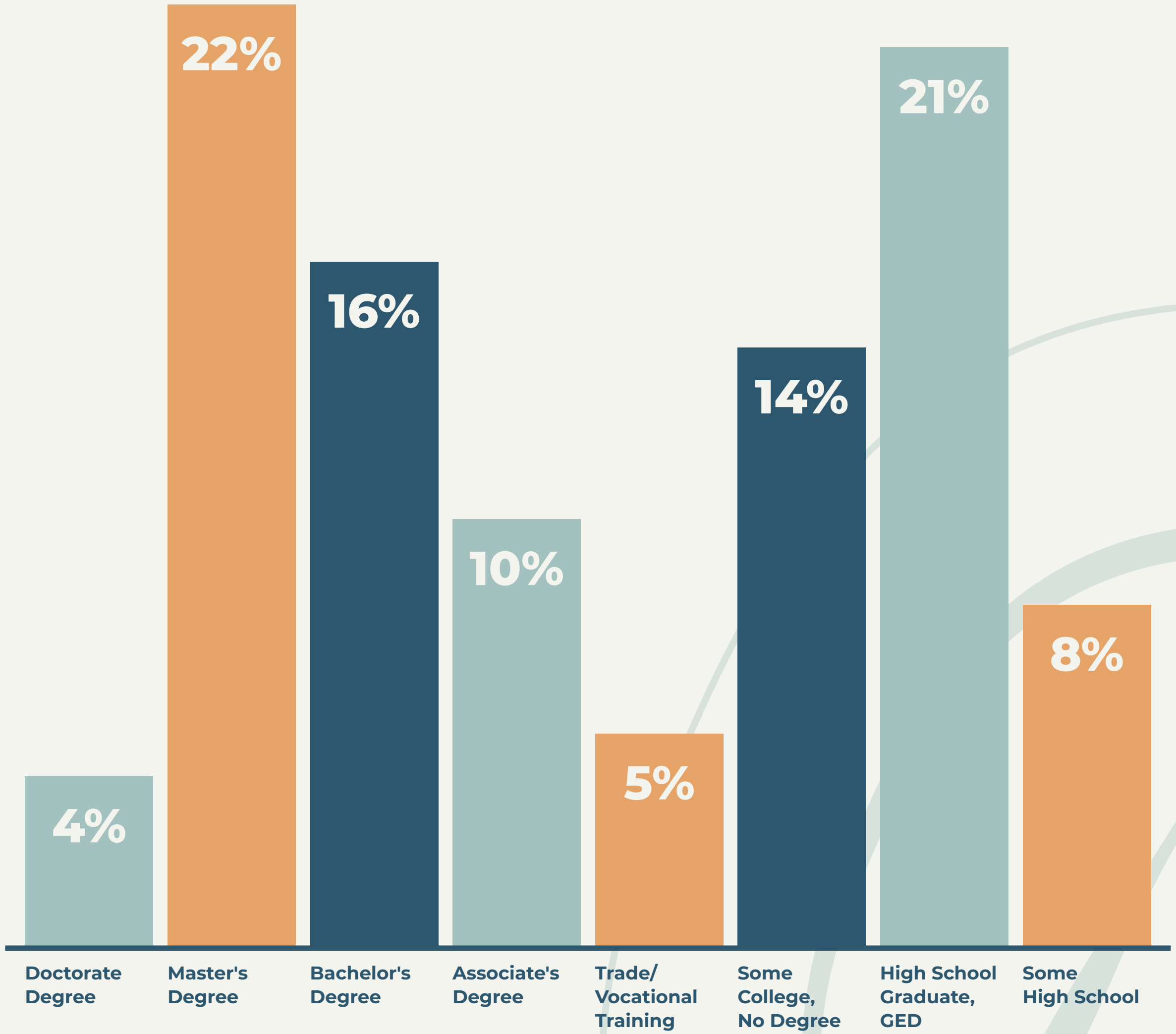
Respondent Demographic: **Education**

50%

earned a college degree or higher.

Key Finding:

Rural American caregivers who participated in this study are well educated, with more than **50% having earned a college degree or higher.**



Respondent Demographic: Age

60%

Rural caregivers surveyed are under 45 years old.

Key Finding:

60% of rural caregivers surveyed are under 45 years old, suggesting a prototype of a younger, Millennial individual caring for an elderly parent or loved one. As shown in other findings from this research, younger caregivers have distinct preferences when it comes to how they communicate with and learn from healthcare providers.

Communication Preferences

Advances in technology have spawned a multitude of ways to communicate and convey information, including information about hospice/home care. People living in rural areas may have practical limitations on how they communicate (e.g., limited access to high-speed internet; inconsistent cellular phone signals), as well as personal preferences regarding communication.

Key Finding:

On average, younger individuals (<45) tend to prefer less direct, asynchronous* forms of communication like text messaging. Older individuals (>55) prefer direct, face-to-face conversations with healthcare providers.

Takeaway:

How you communicate with caregivers about hospice/home care is just as important as what you communicate to them. While some people prefer direct, face-to-face interactions with healthcare providers, other prefer less direct types of communication such as texting or via internet portal. Upon intake, be sure to ask about communication preferences and capabilities to ensure seamless communication with patients, families, and caregivers. If needed, gather contact information for multiple contacts in the event that signal challenges exist.

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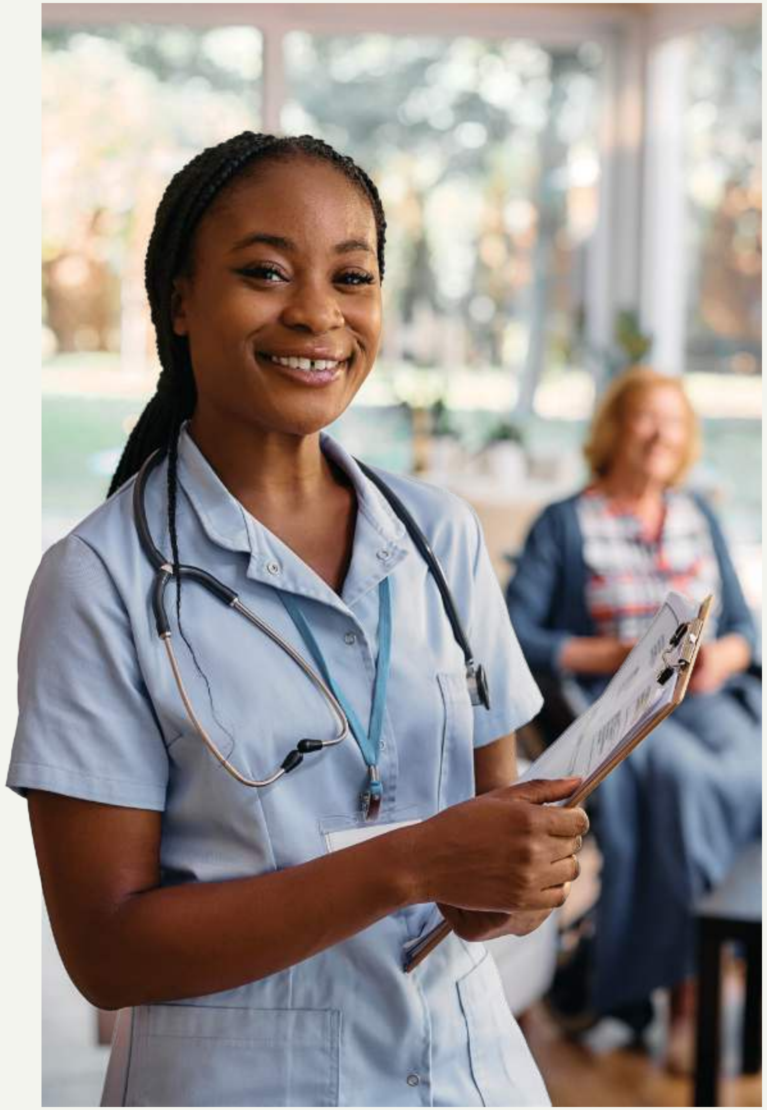
* Asynchronous communication is any type of communication where one person provides information, and then there is a time lag before the recipients take in the information and offer their responses.



Learning Preferences

Similar to communication preferences, learning can be achieved in numerous ways. From digital resources to more traditional printed materials, caregivers have many options for learning about home/palliative care options and related medical subject matter.

Preferred way to received healthcare related information	<45	45-54	>54	Average
Visually: prefers to learn through images, video, and graphics	61%	57%	32%	55%
Reading/Writing: prefers handouts and other written materials	47%	58%	35%	47%
Orally: prefers to have a conversation with a medical professional	58%	65%	70%	62%
Other:	1%	0%	2%	1%

Key Finding:

Younger (<45) caregivers tend to prefer more visual methods of learning like images, videos, and graphics, while older (55+) caregivers prefer learning through direct spoken conversation. Those in the middle (45-54) are comfortable with all learning formats, including reading of written/printed materials.

Takeaway:

One size does not fit all when it comes to teaching caregivers about home/palliative care. Be sure to offer multiple formats for learning to help meet their specific needs and preferences.

Trust in Local Resources

30%

of respondents lack confidence in their local hospitals to provide high quality care.

Key Finding:

While there is a general trust in local healthcare resources, there are some concerns about the quality of care at local rural hospitals.

Takeaway:

A small but significant gap in trust of local rural hospitals presents an opportunity for hospice care organizations to fulfill the unmet needs of eligible patients and their caregivers.

Caregiver Experiences

How do lived experiences shape perception and use of hospice?

> "In the rural community,
>
> doctors may be more hesitant to bring up the end-of-life conversation, so patients and family members are caught off guard when they find out they're close to death."

Rural Hospice Provider

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Impact on Caregivers

Individuals caring for a chronically-ill loved one may at times feel emotionally drained and in need of a break from their responsibilities.

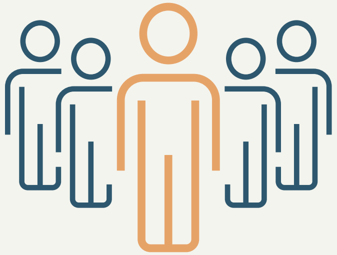
Key Finding:

More than three quarters of respondents agreed to some degree that being a caregiver can be mentally and emotionally exhausting. Similarly, **nearly three out of five respondents** agreed that at times they needed a break from caregiving but were unable to get one.

Takeaway:

Caregiver burnout is a real phenomenon that should be honored and supported with practical solutions. If feasible, offer companionship visits, especially with dementia patients. These types of visits can be particularly helpful when they engage not only the patient, but also family members and home health aides. Respite care can be an invaluable resource for caregivers/family members who need a few days to figure out their long-term plans.

Caregiver Confidence



24%

one in four (24%) did not agree with the statement.

Key Finding:

When asked if they had the confidence to handle the physical and emotional needs of family members/friends in the home, nearly one in four (24%) did not agree with the statement.

Takeaway:

A sizeable minority of caregivers do not feel confident in their ability to handle the physical and emotional needs of their loved ones in the home. This highlights a clear need and role for hospice/home-based care services to provide assistance and training when caregivers don't feel entirely confident that they can manage the responsibilities by themselves.

Hospice Awareness and Beliefs

How does the public's perception of hospice care shape reality?

"Part of meeting patients where they are includes learning about their cultural, spirituality, and traditions. We see patients who are Amish and don't have electricity or phones and patients from the Maharishi community who have their own unique traditions. We've invited them in to help us know how to respect and honor them.

While still meeting their needs."

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Local Hospice Awareness

Even if patients and caregivers are familiar with the offerings and benefits of hospice care, they may not be familiar with hospice options in their local area.

40%

weren't able to name at least one hospice provider that serves their community.

Key Finding:

- More than 40% of respondents weren't able to name at least one hospice provider that serves their community.
- Familiarity with local hospices is greatest with younger (<45) caregivers and least among older (55+) caregivers.

Takeaway:

Ongoing education and marketing of hospice services is needed in rural communities, particularly for older individuals.

Expectations of Hospice

Respondents were asked about their expectations surrounding hospice care, focusing on three specific questions:

- Would hospice workers respect and understand me as a family caregiver for a dying loved one?
- Would a hospice team be able to arrive to the home within an hour, if needed?
- Would hospice provide non-judgmental care?

Key Finding:

- Depending upon age group, between 27% and 42% of respondents had some degree of doubt surrounding these questions.
- The greatest discrepancy was seen among individuals <45, who had the least confidence that a hospice team could show up within an hour, if needed.

Takeaway:

It's essential for hospice organizations to be transparent and realistic with caregivers about how quickly a clinical team could show up when they are urgently needed. To ensure high quality, non-judgmental care is provided, identify local community members or employees (if they volunteer for this) who would be willing to speak to your staff about their cultural traditions and values.

Hospice and Spirituality

Many people receiving end-of-life care are looking for a spiritual component to their care. Caregivers may seek out spiritual support for both their loved ones and for themselves.

Key Finding:

The majority of caregivers would want hospice care to have a spiritual component for both themselves and their loved ones. Those ages 45-54 were most likely to want this spiritual component.

Takeaway:

Care organizations should encourage an open dialogue about spiritual needs and preferences. If patients and/or caregivers express interest, hospice care organizations can engage local clergy to provide collaborative spiritual support.

Building Bridges

How can hospice providers most effectively connect with patients and their caregivers?

"We do hospice presentations wherever we can to inform the public about what it is. Sometimes that's in nursing homes and sometimes it's at the local Kiwanis Club."

Rural Hospice Provider

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Hospice Education: **Who Are Caregivers Looking To?**

The public may learn about hospice from a variety of sources: healthcare professionals, religious organizations, and the hospice organizations themselves.

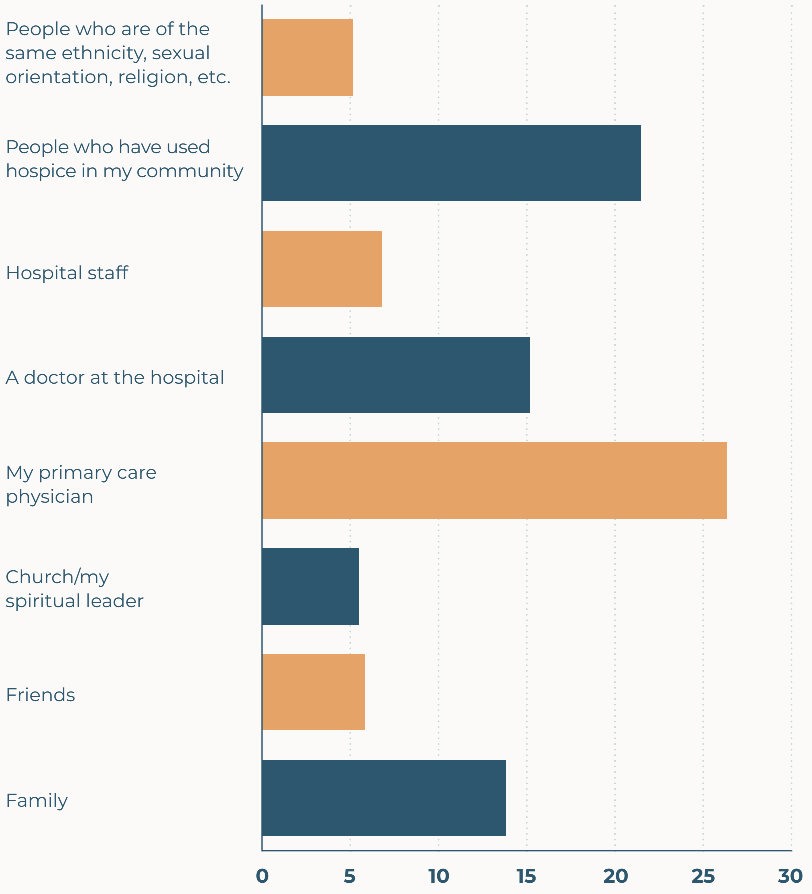
Key Finding:

- For the most part, caregivers are looking to healthcare providers and hospice organizations for education on hospice.
- Some caregivers view religious organizations as sources of hospice education, but this is seen more in younger (<45) individuals.
- When asked who respondents would trust to recommend a specific hospice organization for services, those less than 45 years old and 45-54 were more likely to trust the recommendation of someone who has used hospice in the community. Respondents age 55+ were more likely to trust the recommendation of their primary care physician.

Takeaway:

- Care organizations have an opportunity to provide education about hospice by engaging local community sources and educational institutions (e.g. libraries, community colleges) that promote courses for people age 55+.
- Also consider conducting in-service education with local healthcare providers to dispel any misperceptions they may have about hospice. This can help build partnerships, and ensure that healthcare providers understand when the right time is to bring in a hospice team.

Trusted Recommendations



Hospice Priorities: **What Matters Most?**

Caregivers were asked to rank, by importance, different features of hospice care. Their answers help illuminate priorities of hospice patients, their families, and caregivers.

Key Finding:

- The top stated priority was having hospice be offered wherever the patient lives.
- The next most important feature was hospice workers being able to care for their loved one, so the caregiver could continue to work. This was especially important to caregivers <45 and 45-55.

Takeaway:

Caregivers are looking for flexibility in hospice care, with the ability to have care delivered at home and/or at a nearby location. Both options allow people to continue working, which is especially important to younger caregivers.

Please rank the following where 1 is most important and 5 is least important	1	2	3	4	5	Mean
Hospice can be offered wherever the patient lives	118	61	46	62	51	2.61
Hospice workers can care for my family/ friend so I can continue to work	59	83	84	55	57	2.91
Hospice can help me understand what to expect when a person is dying	37	64	98	78	61	3.18
Hospice provides pain management for the patient	57	80	67	67	67	3.02
Hospice provides support to the family of the patient	67	50	43	76	102	3.28

Acknowledgement

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