


# “We Are Here to Assist All Individuals Who Need Hospice Services”: Hospices’ Perspectives on Improving Access and Inclusion for Racial/Ethnic Minorities

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## Abstract

**Background:** Racial/ethnic minority populations in the United States are less likely to utilize hospice services nearing their end of life, potentially diminishing their quality of care while also increasing medical costs. **Objective:** Explore the minority hospice utilization gap from the hospice perspective by examining perceived barriers and facilitators as well as practices and policies. **Method:** Qualitative surveys were conducted with 41 hospices across the United States. Qualitative data analysis included performing a limited content analysis, including the identification of themes and representative quotations. **Results:** Commonly reported barriers to hospice care for racial/ethnic minorities included culture/beliefs, mistrust of the medical system, and language barriers. A major theme pertaining to successful minority hospice enrollment was an inclusive culture that provided language services, staff cultural training, and a diverse staff. Another major theme was the importance of community outreach activities that extended beyond the medical community and forming relationships with churches, racial/ethnic minority community leaders, and Native American reservations. **Conclusion:** The importance of incorporating a culture of inclusivity by forming committees, providing language services, and offering culturally competent care emerged in this qualitative study. Building strong external relationships with community groups such as churches is a strategy used to increase racial/ethnic minority utilization of hospice.

## Keywords

hospice, health care disparity, race/ethnicity, community

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## Introduction

Hospice utilization is lower for racial/ethnic minorities than for White people, with potential causes for this disparity ranging from sociodemographic and cultural characteristics to disease diagnoses and past negative health care system experiences (Davies et al., 2019; Hanchate et al., 2009; Kelley et al., 2011). Prior research shows there is variation between locations in the magnitude of this utilization disparity and that closing the gap could improve the quality of end-of-life (EOL) care for racial/ethnic minorities and result in nearly US\$270 million in annual Medicare cost savings (Hughes & Vernon, 2019; Kelley et al., 2013). Hospices differ in such aspects as vision, size, ownership status, and type (e.g., freestanding, home health-based), which can influence organizational policies and practices related to outreach and service provision to racial/ethnic minority populations

(Cohen, 2008; Lorenz et al., 2002). With home recently surpassing the hospital as the most commonplace of death in the U.S. hospices (Cross & Warraich, 2019), now more than ever, must focus on developing policies and providing high-quality services to the growing population of patients. This includes ensuring that policies and practices for promoting access to all terminally ill patients are commonplace among hospices.

There exists research exploring cultural competence, the ability to understand, communicate, and effectively

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interact with people across cultures (Crawley et al., 2002), as it relates to EOL care. One such qualitative study highlighted the importance Hispanic patients' families place on cultural preferences during hospice care and suggested having Hispanic employees that could interact with their families as a way for hospices to achieve higher levels of cultural competence (Nuñez et al., 2019). Two dual case studies of how minority patients interacted with their physicians during EOL care highlighted the importance of cultural competency within the medical care community, specifically in regard to decision-making during this period (Crawley et al., 2002; Kagawa-Singer & Blackhall, 2001).

The study herein examines this topic from the point of view of hospice employees. Although there are institutional differences across hospices as noted above, certain outreach strategies may be effective at improving minority hospice utilization and quality of care across a variety of services models, yet are currently employed only at a portion of hospices.

The objectives for this study were two-fold: (a) determine what factors hospice leaders perceive play a role in either preventing or facilitating racial/ethnic minority utilization of hospice and (b) explore the programs and policies of hospices regarding outreach and service provision to racial/ethnic minorities. Although research has examined perceived barriers to racial/ethnic minority hospice utilization from the patient and provider (doctors from training hospitals who specialize in gravely ill patient care) perspective (Periyakoil et al., 2015, 2016), to our knowledge, there is no significant research examining this situation from the hospice point of view. The findings from one qualitative study of 12 hospice and/or palliative care providers or health care organization representatives (the vast majority being nurses and doctors specializing in palliative care but not responding on behalf of a hospice organization) indicated that improvement in cultural competency could potentially increase African American utilization rates and more research should be done in this area (Rhodes et al., 2015). Knowledge gained from the study herein will illuminate key factors hospice leaders highlight within the area of racial/ethnic outreach and service. This information will contribute to more focused quantitative research in the future while also furthering the conversation as to how hospices can more successfully engage in outreach and service of racial/ethnic minorities.

## Method

### *Study Sample and Recruitment Procedures*

Figure 1 shows the recruitment and survey process. We recruited hospices by contacting state hospice organizations (SHO) and asking if they would be willing to forward an invitation to the study to their membership. Of the 50 U.S. States, 44 had an SHO with contact information available online. We chose this method of recruitment to

increase the likelihood that hospices would open up and consider the invitation email. Other than being located in a state that had an SHO, we believe this group of hospices had no special characteristics and was representative of hospice organizations in the United States.

We reached out via email to 44 SHO executives describing our research question, approach, and included an email invitation to hospices to complete our study along with the actual survey. Five SHOs immediately said yes and included the invitation to the study in an email and/or newsletter to their member hospices. After sending a follow-up email, 10 more agreed to send to their member hospices and five agreed to send to their members after more communication with the researchers. Two additional SHOs approved the study but asked the researchers to directly contact each hospice with the study invitation.

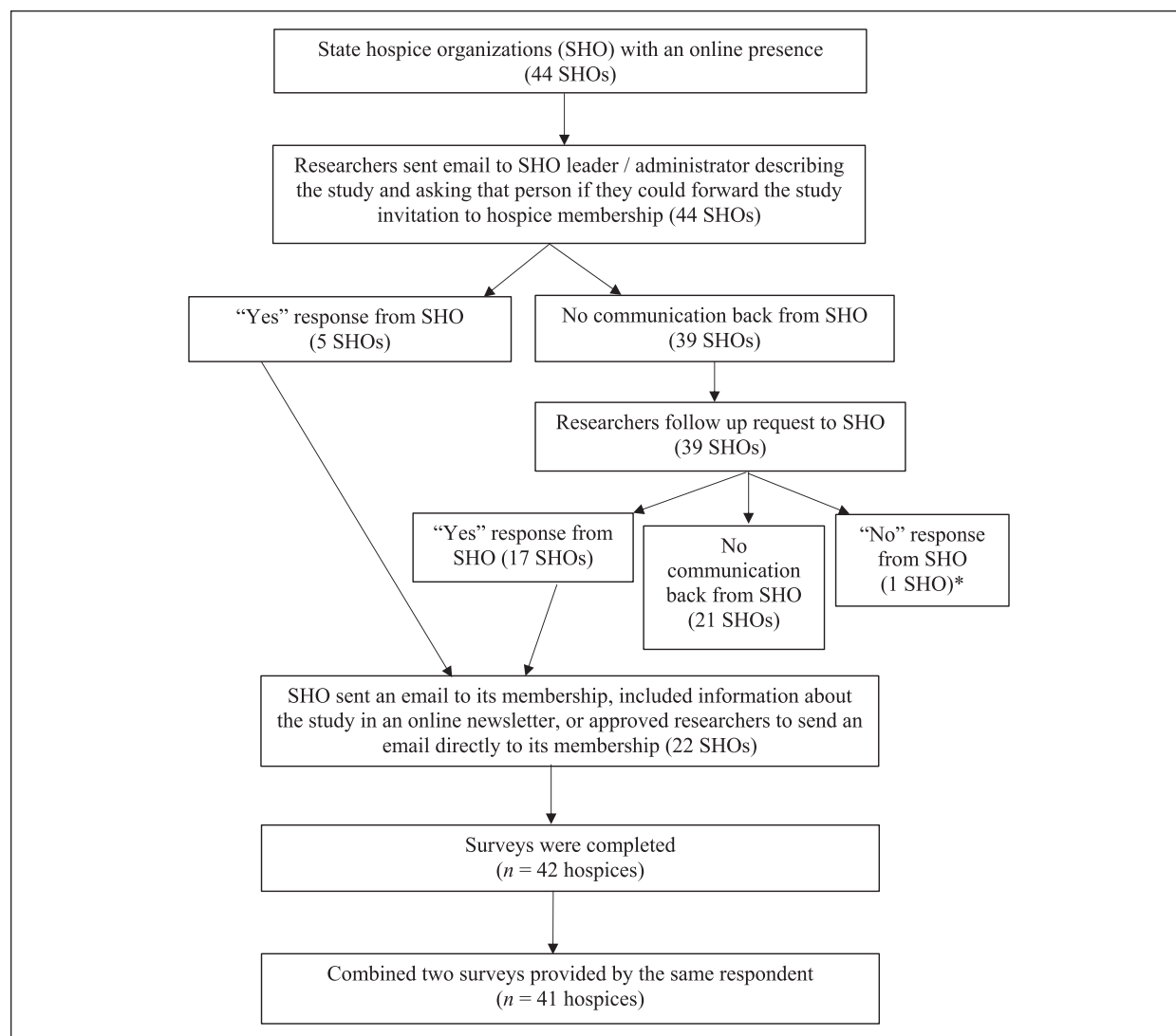
### *Survey Development*

We developed the qualitative survey based on our literature review and guided by our research questions. We made revisions to our survey, which consisted mainly of eliminating redundancy as well as questions where we could instead use external databases (e.g., hospice size), largely to decrease time burden on hospice administrators.

The study invitation specifically requested that someone from the hospice who is knowledgeable about that hospice's policies and practices fill out the survey from that specific hospice's point of view. The survey, comprised of all open-ended questions, explored what factors hospice personnel believed play a role in either preventing or facilitating racial/ethnic minority utilization of hospice. For example, "What factors make it less likely for racial minorities to use your services?" The survey also explored programs and policies of hospices regarding outreach and service provision to racial/ethnic minorities. An example question includes, "What additional services do you offer to patients and their families from minority racial/ethnic groups?" Both Northern Illinois University's Institutional Review Board and Seattle University's Institutional Review Board identified this study as "Not Human Subjects Research" and exempted it from review.

### *Data Collection and Analysis*

For the analysis, the two authors independently coded the interviews. The structure of the survey and main question elements guided the beginning list of codes. After comparing coded transcripts, the authors resolved discrepancies through discussion and developed a detailed codebook. The authors used the qualitative data management software, ATLAS.ti, to perform a limited content analysis, including identification of themes and representative quotations. We limited quantitative analysis to tabulation of responses without statistical testing to keep with the exploratory nature of this study. The chosen quotes represented the nature of other quotes of the same theme.



**Figure 1.** Recruitment and survey process.

Note. SHO declined because the SHO was just forming and did not have an established membership base. SHO = state hospice organizations.

## Results

Of the 42 hospices that completed the survey, one hospice completed it twice. There was no conflicting information in the two surveys, and we combined the two completed surveys to capture all of that respondent's answers. Our final sample size was 41 hospices. We felt we had reached saturation, so did not seek out more hospices for participation. Table 1 provides an overview of the characteristics of the included hospices. Included in Table 1 are the positions of the single individuals who completed the survey on behalf of their specific hospices. The term "respondents" refers to the hospices who completed the survey.

## Barriers

Close to half of all respondents (46%) stated that culture or beliefs among racial/ethnic minorities were barriers to hospice use, and none of the respondents stated that

culture or beliefs among racial/ethnic minorities were facilitators to hospice use. The recurring message was that, for racial/ethnic minorities, hospice is a sign of "giving up," and continuing life-saving treatment is the best way to show they care for the patient. The following quotes illustrate such sentiments:

They believe that hospice is "giving up."

There is a strong desire within minority groups to ensure that everything possible has been done to extend patient life. Some minority groups have strong belief in cures through religious faith. Enrolling in hospice can be seen by them as lack of faith and a decision that will hasten death.

Another barrier to hospice use, according to one fifth of the respondents, was racial/ethnic minorities' mistrust of the entire medical system. Some of the administrators<sup>1</sup> went further to say that the mistrust they observed is warranted. Another respondent summed up the trust barrier:

**Table 1.** Hospice Characteristics.

Characteristic <sup>a</sup>	% (n = 41)
Size (patients/day)	
Extra small (0–19)	13
Small (20–49)	16
Medium (50–124)	37
Large (125–199)	13
Extra large (200+)	21
Ownership	
For-profit	20
Nonprofit	80
Metropolitan status	
Rural	22
Urban	78
Type of hospice	
Freestanding	60
Home health-based	20
Hospital-based	20
Region	
Midwest	44
Northeast	10
South	24
West	22
Role <sup>b</sup>	
Administrator	5
Director/Manager	66
Executive	24
Social worker/Chaplain	5

<sup>a</sup>Source: Hospice Locator (<http://www.nationalhospicelocator.com/>), for all except "Role," which came from the survey.

<sup>b</sup>Characteristic of the person completing the survey, not of the hospice.

We sometimes see an understandable distrust of medical systems in general based on historic as well as personal experience.

Language as a barrier to hospice care was mentioned by one fourth of the administrators. This seemed to particularly be a hurdle when engaging in outreach to local racial/ethnic minority populations. Some hospices mentioned a desire to have marketing materials translated into other languages spoken locally, but not having the staff to create such materials. Furthermore, the majority of respondents who stated language as a barrier also indicated that not having a staff member who speaks the language of a potential hospice patient makes communicating with and providing care for that patient difficult. One respondent summed up the language roadblock to hospice use in a simple equation:

No staff available to speak a certain language = less likely for that minority to sign on.

### Language and Culture-Related Facilitators

Providing language services was the most common practice noted for improving minority hospice use.

Over 70% of the surveyed hospices mentioned the use of language services as one of their approaches to improving both minority hospice participation and quality of care. Similar to what was noted in the barriers, the 10 hospices with multilingual staff or volunteers highlighted the most success in this area, followed by 13 hospices with in-person/online interpreter services. The eight that mentioned they only had language line services available were generally not as positive about this service when compared with having multilingual staff or local interpreter services:

We have a number of Hispanic families in [location] and language can be a barrier to care but we presently have 2 nurses who speak fluent Spanish. We also have full time language translation services and an interpreter phone for our use when we go to patient's home.

We have medical interpreter services using an application where they can "face-time" each other. All our clinicians have access to this app at any time from their mobile devices.

Having a diverse staff was recognized by one third of the hospices as a significant driver for increasing diversity among their patients. Over half of the surveyed hospices that reported a racial/ethnic minority population of 20% or higher explicitly noted the importance of a diverse staff for minority recruitment and trust:

When patients and families can relate to the staff and have the opportunity to be cared for by the same ethnicity they are more likely to trust and enroll in hospice services.

In addition to staff diversity, over one third of the hospices surveyed noted they had implemented staff cultural training to serve their minority communities better:

First, we needed to educate ourselves. Our education surrounding cultural humility has been extensive.

It can be very difficult to provide services to the above populations if we aren't able to learn about the culture and respect the cultural differences.

### Outreach Activities

Over 60% of the surveyed hospices mentioned that they have outreach activities specifically geared toward minority populations. Around half of the outreach activities include forming relationships with a church or other religious communities, while others mentioned forming connections with minority community leaders, immigration outreach organizations, Veterans' Affairs, and targeted health service programs:

Our organization has begun targeted community events that are designed to specifically be advertised in a particular

minority group. These recurring events with varying topics has helped to engage the community in more discussions about health care in general, as well as end of life care.

Ongoing collaboration with faith communities has been essential in providing this care.

Multiple hospices discussed how community connections not only foster stronger relationships across racial/ethnic boundaries but also provide the opportunity for two-way education:

Outreach efforts within minority populations help make it more likely for minorities to use our services, increasing awareness of the services we provide. Having connections within minority communities helps make it easier to provide services to minority populations. Connecting with communities to understand first hand from them how they perceive hospice, what their needs are, etc. (rather than make assumptions).

We have built relationships with the [name] Indian Reservation. They have brought staff to our staff meetings and they also provide us education on Native American traditions.

Six hospices highlighted that having peer referrals have aided them in overcoming the trust obstacles within the minority communities:

We have had a situation where one patient/family was able to share their experience with others in their same ethnic community—which opened up others to the idea of hospice services being welcomed.

### ***Inclusionary Policies***

Over one third of the hospices indicated that they had inclusionary policies. The majority of this group did not mention formal committees or policies but noted an overarching practice of acceptance:

We don't have specific policies as we treat all patients with dignity and respect, regardless of ethnic or socioeconomic differences.

We are here to assist all individuals who need hospice services.

Nine hospices had established formal committees devoted to racial/ethnic equity and inclusion. Most of the groups appeared to be in the exploratory phase in regard to educating themselves on how to best reach and serve the minority populations within their areas:

This year we have developed a Diversity, Equity and Inclusion Council that is initially looking at how we address these issues internally to create a diverse, equitable and inclusive workplace but that we hope will also translate into our practices and policies.

We have an active equity and inclusion committee that meets monthly and works on furthering our capability and capacity to serve minority communities.

### ***Differences***

Over two thirds of the hospice administrators surveyed stated that they have noticed differences related to hospice for White patients and their families compared with racial/ethnic minority patients and their families. Of those administrators who observed differences, 30% indicated that racial/ethnic minority families provide more support to the hospice patient than the amount of support provided by White families to their hospice patients. The following quotes reflect the perceived importance of providing "hands-on" care among racial/ethnic minorities for a family member in hospice care:

Racial/ethnic minority patients at times involve the family unit more. During the admission process, there may be a need for the patient or health surrogate to identify 10-12 family members who need to be involved. Families tend to be larger in visitation.

Asian and Hispanic families tend not to place patients in facilities, but consider it their duty to provide hands on care.

In most cases the African American and Hispanic families have additional support systems to aid in caregiving roles in the home where many anglo-Saxon use external resources like nursing facilities.

The Native American families tend to gather and stay with a family member for days and weeks at a time. They seldom only have 1 or 2 family members like non-racial families . . . It is not uncommon to have 30-40 people gathered for days or weeks in a small one bedroom apartment.

Related to the hospice administrators' view that racial/ethnic minority families tend to provide more support is the location of that support, which is often-times the home rather than a hospital or medical facility. Although one administrator indicated that the desire for death at home makes racial/ethnic families more open to hospice, a few administrators stated it is an impediment to hospice care because families may fear loss of control or responsibility. The following quotes express the perceived significance placed on dying in the home:

Ethnic minorities are more private and apt to have a tradition of caring for the elderly at home.

Fear of having outside individuals in their home and their loved one having to be removed from their home due to poor conditions or lack of ability to provide adequate care by the family/caregivers.



## Discussion

Two key themes emerged regarding hospices that reported relatively successful outreach to racial/ethnic minority populations. First, hospices often incorporated a culture of inclusivity, which included forming committees, offering language resources to patients and providing cultural training to staff. Second, hospices often built strong external relationships outside of the medical care silo with trusted members of the minority communities.

Hospices which adopted a culture of inclusivity that appeared to permeate throughout their business systems and practices consistently reported that such efforts made it more likely for racial/ethnic minorities to use their hospice services. A culture of inclusivity often included forming a committee focused specifically on goals related to equity and anti-discrimination. An important role these committees could play is to provide standardized evaluation processes for their inclusion and outreach programs, as suggested by related research (Tan et al., 2012). Given the scarcity of hospice resources, it is paramount to understand whether various approaches used to improve minority care and utilization are effective. This study suggests that committees specifically geared toward inclusivity practice are often deemed successful by hospice leaders and thus warrant further quantitative studies in terms of overall effectiveness.

Hospices that enhanced their service offerings and offered staff training to meet the needs of diverse patients reported better outreach to racial/ethnic minority populations. Several hospices highlighted that providing quality language resources is imperative to educating prospective patients and families and facilitating care for enrolled patients. Other internal practices noted as highly important for recruiting and serving minority communities were having diverse staff/volunteers and providing cultural training to all staff. These practices are consistent with research findings based on the point of view of providers and patients (Periyakoil et al., 2015, 2016; Rhodes et al., 2015).

The importance of an emphasis on cultural competence is not surprising, given the marked differences that were reported for White patients and their families compared with racial/ethnic minorities and their families. For example, staff members should have an awareness of the greater likelihood that members of racial/ethnic minority populations have a mistrust of the health care system (Kennedy et al., 2007; Wynia & Gamble, 2006), which may be relevant for anticipating fears such as one expressed in this study of the health care system removing a patient from home upon seeing the living conditions. Wittenberg-Lyles et al. (2012) suggested taking training a step further to account for the type of family caregiver involved and the communication style that would work best. They described four caregiver types: manager, carrier, partner, and loner and suggest that clinicians prepare for communication with each of these types of caregivers.

Several hospices noted that building strong external relationships with trusted members of the racial/ethnic minority communities within their geographic region was a critical step toward improving both outreach and service quality. This is in line with a recent study that conducted a focus group of members of African American churches and concluded that hospice collaborations with African American churches could successfully improve the understanding of hospice care (Johnson et al., 2016). However, research suggests that community outreach, in general, has been an area of weakness for U.S. hospices (Dussen et al., 2011; Hiatt et al., 2007). Whether through churches, nonprofit service organizations, or other minority support programs, hospices in our study with these external connections noted an increase not only in minority participation but also the internal level of knowledge about how to better provide and serve these populations. Those who have had success in forming community relationships also mentioned that peer referrals had become a critical factor in overcoming the trust barrier often noted for minority hospice utilization.

Our study had both strengths and limitations. A strength of the study is the access it provides to hospice personnel viewpoints, which is valuable for understanding the facilitators and barriers as well as policies and practices as they relate to racial/ethnic minority utilization. Also, hospices across the nation and of varying sizes and types were included in the study, allowing the findings to extend beyond just one geographic area or type of hospice. Limitations of the study include the high likelihood of selection bias in that hospices who chose to participate in the study may be more interested in issues related to hospice utilization for racial/ethnic minorities. In addition, the study used self-reported data and there is a possibility that respondents answered in way they thought would please the researchers.

With significant disparities existing in hospice utilization between White people and racial/ethnic minorities, increasing outreach to underserved populations by building trust through community relationships and offering inclusive services are possible strategies for more hospices to consider. Hospices located in geographic areas with significant racial/ethnic minority populations, in particular, may benefit from taking steps that better educate and welcome all terminally ill individuals. By following the growing trend in health care to improve cultural competence and making a targeted effort to form relationships with community minority groups, hospices can more effectively recruit and serve racial/ethnic minority groups.

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## Note

1. The authors use the term “administrators” to refer to any of the respondents, even if the particular job title of a particular respondent is a different term (e.g., “director”).

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