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US hospices' approach to racial/ethnic minority inclusion: a qualitative study

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ABSTRACT

Objective To examine hospices' approaches to improving the current racial/ethnic hospice utilisation disparity.

Methods During June and July 2020, we conducted in-depth, semistructured interviews with 22 hospice leaders from across the USA. The interviews focused on inclusive strategy approaches. We analysed the data using qualitative methods.

Results Multiple themes emerged about racial/ethnic minority inclusion strategies: (1) hospices tailor strategies to the local communities they serve; (2) improvement involves addressing social determinants of health that extend beyond end-of-life care; (3) costs of strategies are not a primary concern and the benefits are worth the costs; and (4) hospices want to do more to improve their efforts.

Conclusions Hospices want to improve racial/ethnic minority inclusion and can take specific action steps to educate community members about hospice and provide an environment within hospice care that is welcoming to all. Hospice-targeted programmes and policies that facilitate language translation, diversity in staffing, enhanced community outreach, and leadership and staff collaboration regarding inclusion may help hospices achieve success in their efforts toward racial/ethnic minority inclusion.

Key message box

What was already known?

- Racial/ethnic disparities in hospice utilization exist.
- Cultural beliefs, treatment preferences, and differences in knowledge contribute to disparities.

What are the new findings?

- Tailoring local community outreach and addressing social determinants of health may improve inclusion.
- Hospices want to do more for inclusion.

What is their significance?

- More hospices engaging in inclusion strategies may help close the disparities gap.
- The time is now for improving hospice inclusion especially given the current pandemic and social dialogue.

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BACKGROUND

Research shows that providing comfort care in the form of hospice to patients nearing the end of life is an effective approach to improving their quality of life¹ as well as the experience for the decedent's family members.² Hospice care refers to a team-oriented approach to medical care, pain management, and spiritual and emotional support for terminally ill patients and their families.³ In the USA, for example, the number of

Medicare beneficiaries annually receiving hospice care has grown by over 17% from 2012 (1.27 million) to 2017 (1.49 million).⁴ While Medicare beneficiaries from all major races and ethnicities in the USA have increased their hospice utilisation, rates for racial/ethnic minority groups continue to be significantly lower than the white groups'. In 2017, 33.8% of white Medicare decedents died under hospice care while the rates for black, Hispanic, Native American and Asian decedents were 28% or less. This racial/ethnic minority group disparity in hospice utilisation exists even when controlling for socioeconomic factors such as age, income, education and area population,^{5 6} and is also experienced in the UK.⁷

There is a wide range of reasons why racial/ethnic minority populations do not use hospice services, including differences in knowledge, cultural beliefs and treatment preferences.⁸ The concept of pain

and death can also vary by culture. In some ethnic cultural groups, death is typically not discussed, or if discussed, carries a significant spiritual meaning that can often go hand-in-hand with culturally deep-rooted traditions.⁹ Research shows that black populations, specifically, often do not use hospice because of spiritual and religious beliefs, mistrust of the healthcare system and concerns about racial prejudice.^{8 10}

While there is ample evidence showing lower racial/ethnic minority group rates of hospice utilisation,^{5–7} there is minimal research investigating the strategies hospices can employ to address this issue. We build on recent exploratory research that suggests that within hospices, incorporating a culture of inclusivity through forming committees, engaging in outreach education programmes, providing adequate language services, and offering culturally competent care can lead to improved quality and/or utilisation for racial/ethnic minority groups.¹¹ To our knowledge, our study is the first to examine these strategies in detail to help understand specific actions that hospices find effective as well as any related costs and benefits of inclusionary strategies by hospices for racial/ethnic minority groups.

METHODS

In June and July of 2020, we conducted in-depth telephone interviews with hospice leaders across the USA about hospice inclusion for racial/ethnic minorities. The interviews averaged 30 min in length. Interviewees were informed that their names and hospices would not be individually identified in any report created from the project.

We identified potential hospice leaders from across the USA to participate from the researchers' hospice contacts, National Hospice Locator¹² and state hospice organisations. We recruited participants by sending email invitations to 250 hospice leaders over 1 month in three different waves. We asked them if we could interview them or a member of their professional team 'to learn more about the costs and benefits regarding hospice inclusionary practices and policies.' We further stated that the 'questions will mainly centre around what, if any, inclusion activities you offer (eg, language services, cultural competency training for staff, community outreach and equity-focused personnel/committees).' As a token of our appreciation, we offered \$20 for their time and participation. An additional follow-up reminder email invitation was sent 1 week after the first email. The individuals who responded with interest were sent an informed consent email and then divided equally for telephone interviews across three researchers trained in qualitative data collection (MCH, EV, MK). Each participant gave oral informed consent to participate at the start of the interview.

We conducted semistructured interviews to explore more deeply hospices' practices and perceived costs and benefits from offering potential areas of focus

for racial/ethnic minority group inclusion identified in a previous study: (1) language service offerings, (2) cultural competency training (CCT), (3) outreach activities, and (4) diversity, equity and inclusion committees. We defined racial/ethnic minority groups as non-white and/or Hispanic populations. The open-ended question format encouraged participants to raise points that were important based on their experiences. The interviewer took detailed notes while conducting each interview and recorded any additional observations immediately after the interview.

The researchers first reviewed all transcripts and then developed a coding structure. Codes were iteratively developed by the interview guide and examining the data. The qualitative data analysis tool Dedoose V.8.0.35 (SocioCultural Research Consultants, www.dedoose.com) was used to code and categorise interview responses. Phrases were independently coded by two researchers (MK, MB-R). Conflicting data were discussed by all four researchers until a majority resolution was reached. The researchers collaborated to organise the codes into themes that were related to specific concepts and ideas. Throughout the entire process, transcripts were continually reviewed to verify themes accurately reflected the original interview content. The 22 interviews allowed the researchers to reach thematic saturation, which they determined using a saturation table.¹³ The chosen quotes represented the nature of other quotes of the same theme.

RESULTS

Twenty-two hospice leaders completed in-depth interviews. Hospices ranged in size from small (0–49 patients/day) to extra large (200 or more patients/day), were primarily non-profit (64%) and were evenly spread out across the different regions of the USA. The majority of the interviewees representing the hospices were either the chief executive officer or held another executive title (63%) with the remaining representatives holding director-level titles (table 1).

Language and diversity

All of the hospices reported having access to some language translation services. Remote language translation services, as opposed to in-person translation services, were most common, with modalities varying from telephone based to video translation. Several hospices noted that remote language translation costs can get high when used frequently, but these services often go mainly unused. Hospices reported that service contracts could be a monthly flat fee ranging from \$200 to \$300 or paid on a per-minute, per-call or per-hour basis, with \$1, \$6 and \$50 provided as example rates, respectively. A few hospices did not know the cost of their language services due to a larger hospital system owner covering the cost.

A reason for not using remote services was that some hospices preferred in-person translation in the form

Table 1 Hospice characteristics

Characteristic	No (%)
Size (patients/day)	
Small (0–49)	6 (27.3)
Medium (50–124)	4 (18.2)
Large (125–199)	4 (18.2)
Extra large (200+)	8 (36.4)
Ownership	
For-profit	8 (36.4)
Non-profit	14 (63.6)
Metropolitan status	
Rural	4 (18.2)
Urban	18 (81.8)
Region	
Midwest	7 (31.8)
Northeast	4 (18.2)
South	5 (22.7)
West	6 (27.3)
Role*	
Chief executive officer	12 (54.5)
Other chief level	2 (9.1)
Director/manager	7 (31.8)
Mission officer	1 (4.5)

*Characteristic of the respondent, not of the hospice.

of a trained and certified translator (reported costs ranging from \$30 to \$50) or bilingual staff member. The bilingual staff members included nurses, doctors, social workers, community outreach workers and chaplains. Additionally, hospices sometimes did not use in-person translation services because a patient's family member translated instead. Hospices differed in their views about the appropriateness of a patient's family member translating, with some opting for this method because it provides comfort and meets the patients' and families' wishes. In contrast, others were concerned that it results in the family member translator making the ultimate hospice-related decisions rather than the patient. Also, it may put family members in an uncomfortable position of explaining challenging situations.

Another strategy employed by multiple hospices was hiring bilingual staff members. Typical reported additional salary costs for bilingual staff versus non-bilingual staff ranged from \$1000 to \$1500. In general, hospices stated the extra costs associated with hiring bilingual staff or offering translation services were worth it and resulted in serving more diverse populations.

Benefits that hospices mentioned from breaking down the language communication barrier between staff, patients and their families were providing enhanced care, breaking down fears and helping with hospice education. A majority of the hospices reported that having language capabilities helps fulfil language and cultural needs. One hospice summed up

the benefits to both the healthcare providers and the families:

Providers can have faster decision making, better understanding of needs or wants of families, and families are more comfortable when able to speak in their native language.

Cultural competency training

All but one hospice included in the study provide some CCT to their staff. The majority reported doing so annually, if not monthly, and many train staff on joining their hospice, too. The source of CCT offered by the hospices varied from being internal, external or both. Nearly half of the hospices reported delivering their training online, and most of those hospices contract with an external online education vendor for this service.

When asked about the costs of CCT, most respondents did not know how much their hospice spent on such training. Of those who did know, the costs varied widely, ranging from virtually nothing except minor staff time costs because the executives and social workers provide the teaching to paying an online vendor \$15 000 per year for multiple courses for their staff. There were also one-time costs for some hospices who provide multiple-day workshops on cultural competency and diversity or send employees to state and national conferences where they learn about these topics.

Often, the specific content or focus of the CCT training was tailored based on the hospice's location and the specific cultures prevalent in their communities. When the community had high densities of racial/ethnic minority groups, the hospice frequently turned to their staff members or chaplain who knew that specific culture. In these cases, staff members would speak to the entire staff about that culture's general beliefs about death, recommended terms to use and cultural practices surrounding death. Larger hospices reported creating binders of information for each culture that staff could examine before communicating with racial/ethnic minority groups or patients and their families.

About half of the respondents commented on the positive impact CCT had on their work, including connecting better with patients and improving quality of care. The staff gained a better understanding of their patient communities and cultures, and one respondent stated that staff wanted to continue this education, so they formed a staff diversity council. The following quotes illustrate sentiments about the benefits of training:

Big, positive impact on both patients and staff. Significantly [improves inclusion]. Since we started 4 years ago the number of patients we serve has been a huge increase.

Several hospices reported using the Consumer Assessment of Healthcare Providers and Systems Hospice Survey results to measure the impact of their CCT. Some also expressed a desire to measure the impact of CCT more. While there is a general view that CCT is beneficial, there is a lack of useful quantitative measures.

Outreach

Hospices consistently reported that outreach beyond the medical community is critical for building trust and long-term relationships with surrounding communities. Many of the hospices use their staff to perform outreach activities and find that this is a successful approach for increasing utilisation rates among racial/ethnic minority groups. Although several hospices stated having specific marketing personnel allocated for general outreach purposes, there were no indications that these individuals specifically improved outreach success within racial/ethnic minority communities. Financial costs associated with outreach varied anywhere from thousands to tens of thousands of dollars annually.

Most hospice outreach consisted of forming relationships and providing education about hospice to the local community. Several hospices described activities that went outside of the scope of hospice care and education in order to help meet their communities' diverse needs. Examples of such outreach include attending lesbian, gay, bisexual and transgender pride month events and helping fund technology access for children during the COVID-19 pandemic. Some hospice leaders discussed addressing patient families' social needs by providing extra goods like groceries and diapers and connections to community social services like transportation and childcare. One hospice summed up the holistic nature of their patients' and families' needs:

All these things are interconnected--hunger, health disparities, education.

Estimated time spent on outreach varied widely across hospices, from 3 to 650 hours per month. Almost all hospices mentioned education as being a component of their outreach. About one-third of the hospices conduct their outreach across various media channels, translated in languages most commonly used within their services areas. About one-half of the hospices partner with other organisations such as non-profit aid groups and community cultural centres to help reach their outreach goals.

Many hospices said that although obtaining referrals is certainly a benefit of their outreach efforts, their main initiative is to build trust among diverse communities and foster long-term relationships with community members. Multiple participants emphasised the significance of consistency in building trust. One hospice expanded on this, explaining how outreach

can negatively impact trust when it is performed once without follow-up in the following weeks.

We want them to trust us first and see that we care, before going straight into hospice education. Don't pop in and pop out; anyone who is doing this work needs to be consistent.

Over half of the hospices interviewed stated they want to do more outreach specifically to racial/ethnic minority groups. A few even noted that this interview would spur them on to have internal or external conversations about outreach strategies. Several hospices mentioned wanting to reach more of their communities' black population through outreach.

We want to better serve our African American community and are looking for advice related to this.

Committees

One-third of the hospices have established committees that focus on diversity, equity and inclusion. Another one-third, either recently (within the past 3 months), formed a committee or plan to soon. The final one-third do not have a committee nor intentions to establish one in the near future.

The majority of those with newly formed inclusion committees cited recent current events highlighting racial/ethnic minority group disparities within the US healthcare system as an impetus for establishing them. Another recently formed diversity committee resulted from employees requesting its establishment after a well-received focus on CCT. Multiple hospice leaders expressed a desire to make sure the committees were effective in promoting and facilitating a more inclusive environment for staff and patients and simply not a 'check off the box' step. The leaders acknowledged that these committees have a significant task ahead of them.

It will be hard to change systemic processes that have been in place that have promoted these disparities over the years.

Of the one-third with established inclusion committees, there was unanimous agreement that the committees' benefits outweighed the costs. All committees had staff as members (usually volunteers), with many also including members from their board or other areas of a hospice's hospital system. Meetings ranged from every 2 weeks to every other month with one committee meeting on an 'as-needed basis.' Specific actions included reviewing online material, marketing material, and all other communications from a diversity lens, reviewing patient and staff demographics, and strategising about inclusion goals and activities. Costs associated with committees were noted as minimal across all hospices. The benefits from having such committees included reported increased inclusion rates (found by hospices comparing their racial/ethnic

minority individuals enrolment data before and after committee formation for those hospices that collected such data), a safe place for staff (especially racial/ethnic minority employees) to share ideas/concerns, and increased accountability for both inclusionary human resource practices and making sure inclusion remains a priority for the organisation.

Gives employees a voice, particularly minority employees.

Allows a place to strategize on ways to be more inclusive, hold each other accountable, set goals.

DISCUSSION

Our results suggest that hospices have a desire to improve racial/ethnic minority group inclusion for end-of-life care patients and families, and can play an important role in reducing the existing disparities in end-of-life care. We found that tailoring strategies to the local population and helping the community meet needs that extend beyond end-of-life care may be especially effective approaches in establishing trust with community groups, the local population, and patients and their families. Using a community-level approach and addressing the social determinants of health is in line with the key strategies led by the US Department of Health and Human Services' Office of Minority Health to reduce racial/ethnic disparities in health and healthcare, in general.¹⁴ Another key finding of the study was that hospices were not that focused on the costs of inclusionary strategies and usually believed the benefits resulting from these strategies outweighed the costs.

Whether related to language services, outreach, training or committees, it was an underlying theme that hospices tailor their inclusion strategies to the communities they serve. This is in line with an international review of qualitative research on the hospice and palliative care experiences of patients from non-Western and minority cultural backgrounds. The review emphasised the importance of hospices addressing communication, perception of hospice and cultural beliefs in ways that are specific to local minority populations.¹⁵ In the USA, race and ethnicity correlates with residential areas,¹⁶ making specific languages and cultures more prevalent in certain communities. With limited time and resources to devote to CCT, it makes sense to focus on staff developing a better understanding of those cultures in need of services within the community. This theme is consistent with past research describing how individual hospices have engaged in training to learn about local cultures and traditions as they relate to death and palliative care.^{14 17} Additionally, hospices can engage their chaplains to conduct training if they have knowledge to share about the specific spiritual beliefs and practices surrounding death for local racial/ethnic groups.

Staff diversity can contribute to a welcoming atmosphere for racial/ethnic minority groups particularly when staff members are of the same race and ethnicity as patients.¹⁸ One method for achieving such diversity is by hiring members of local racial/ethnic communities. These individuals have an understanding of the specific language and culture and also have ties to the local community which can be beneficial for outreach initiatives.

One aspect for hospices to keep in mind when tailoring their inclusion strategies for local racial/ethnic populations is not to neglect the black population. Often, the emphasis is placed only on language translation and learning about the different connotations of words such as 'hospice' in other languages. This was highlighted in one of our interviews with a hospice that has received commendations for its work in improving access within Hispanic and Asian communities, largely due to addressing the language barriers. This hospice highlighted that they have yet to improve inclusion rates for the black English-speaking community, citing that the barriers extending beyond language have been harder to overcome. Understanding and addressing barriers to hospice related to values, cultural beliefs and monetary concerns, to name a few, for the black population is necessary to improve the disparities between black and white hospice utilisation.^{8 19}

Organisations can engage in outreach to disseminate information to their target population and better deliver services.²⁰ The hospices in this study discussed ways in which they went 'above and beyond' in outreach to their local communities. Several hospices addressed the social determinants of health in their community and for the families they serve. One reason for this social services-oriented outreach approach may be that hospice leaders often have a background in social work and experience working at other social services organisations.²¹ This holistic focus on patients and their families' needs went hand-in-hand with hospices building an overall sense of trust and goodwill within the communities they serve.

Overall, the costs of inclusionary strategies were not a primary focus for the hospices in this study, and hospices expressed that the benefits of inclusion efforts outweighed the costs. The value of inclusion efforts was particularly noted when it came to hiring bilingual staff members. Multiple hospices had calculated the costs and benefits of hiring bilingual staff and reported that the extra costs paid for themselves in a relatively short time period. In several instances, the hospice leaders did not know the costs of their inclusionary measures, which in some cases, was due to cost absorption by a larger health system owner. The participation of more non-profit hospices (63.6%) versus for-profit hospices may also be a factor in the hospices showing a lack of concern about costs because non-profits are not expected to provide a return on investment to shareholders. This finding may suggest that, when

approaching hospice leaders, inclusionary advocates and programme designers should stress the potential benefits of inclusionary policies and programmes over addressing cost barriers.

The hunger to do more to improve racial/ethnic inclusion evident in the majority of interviews likely reflects industry trends and the events affecting our society in 2020, namely COVID-19 and the race-related international dialogue following George Floyd's death in Minnesota. Serving racial/ethnic minority groups is also at the forefront during the COVID-19 pandemic as these populations have experienced higher hospitalisation and death rates than non-Hispanic white population.²² Additionally, the numerous media stories related to racial issues and heightened awareness about equity create an ideal time to address disparities in hospice utilisation among racial/ethnic minority groups.

Our study suggests one best practice for hospices that are just starting to employ inclusion strategies would be to form a committee focused on this area. All but one of the hospices in this study that reported successful inclusionary approaches had a committee focused on improving success in this area. Taking the low-cost step of forming a committee can provide accountability and a knowledge base for current and future needs related to serving minority populations.

Hospices alone cannot eliminate the racial/ethnic hospice utilisation disparity. Federal policies aimed at promoting hospice training for medical students and increasing hospice care reimbursement to primary care providers may provide increased access not only to racial/ethnic minority groups but also to other underserved groups (eg, rural, low-income). Additionally, policies and programmes focused on providing education and benefits for community-based palliative care may help patients and families in need of comfort care receive these benefits earlier on in their disease trajectory.

Our study had both strengths and limitations. A strength of this study is the access it provides to hospice leaders' viewpoints and experiences regarding racial/ethnic minority group inclusion strategies. Furthermore, hospices of varying sizes and types across the USA were included in the study, increasing its relevance beyond just one category of hospice. However, one limitation may be that the majority of hospices in the study (81.8%) were in urban (vs rural) areas, decreasing its relevance to rural areas. Another limitation of the study is the high likelihood of selection bias. The respondents were hospice leaders who responded to our email invitation inquiring about being interviewed about racial/ethnic minority hospice inclusion and, thus, more likely interested in this topic. While the majority of respondents had intentionally incorporated minority group inclusion strategies with varying levels of perceived success, three respondents mentioned they have not done any work in this area but wanted

to learn more. Additionally, the data are dependent on hospice leaders' self-reported information. There is a possibility that the respondents answered in ways they thought would please the interviewer and describe their hospice in the best light. Future investigation of the perspectives of hospice staff members may provide more insights into hospice inclusion issues.

This study provides new insights into hospices' experiences with improving racial/ethnic inclusion. These data can help hospices understand strategies that may be useful in educating racial/ethnic community members about hospice and providing an environment within hospice care that is welcoming to all.

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