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What are Hospice Providers in the Carolinas Doing to Reach African Americans in Their Service Area?

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Abstract

Background: Experts and national organizations recommend that hospices work to increase service to African Americans, a group historically underrepresented in hospice.
Objective: The study objective was to describe strategies among hospices in North and South Carolina to increase service to African Americans and identify hospice characteristics associated with these efforts.
Methods: The study was a cross-sectional survey using investigator-developed scales to measure frequency of community education/outreach, directed marketing, efforts to recruit African American staff, cultural sensitivity training, and goals to increase service to African Americans. We used nonparametric Wilcoxon tests to compare mean scale scores by sample characteristics.
Results: Of 118 eligible hospices, 79 (67%) completed the survey. Over 80% were at least somewhat concerned about the low proportion of African Americans they served, and 78.5% had set goals to increase service to African Americans. Most were engaged in community education/outreach, with 92.4% reporting outreach to churches, 76.0% to social services organizations, 40.5% to businesses, 35.4% to civic groups, and over half to health care providers; 48.0% reported directed marketing via newspaper and 40.5% via radio. The vast majority reported efforts to recruit African American staff, most often registered nurses (63.75%). Nearly 90% offered cultural sensitivity training to staff. The frequency of strategies to increase service to African Americans did not vary by hospice characteristics, such as profit status, size, or vertical integration, but was greater among hospices that had set goals to increase service to African Americans.
Conclusions: Many hospices are engaged in efforts to increase service to African Americans. Future research should determine which strategies are most effective.

Introduction

Over the last decade there has been a substantial increase in the use of hospice by African Americans, a group historically underrepresented in hospice. Between 2000 and 2012, rates of hospice use among African American Medicare beneficiaries increased from 17.0% to 36.7% and among whites from 23.8% to 49.0%.[1] Despite the persistent racial gap in hospice use, these data document some progress in expanding access to high-quality end-of-life care to African Americans. This may be due not only to an increase in availability and accessibility of hospice but also to its acceptability among African Americans as a result of initiatives to address potential barriers to hospice use.[1–8]

The most commonly cited barriers to hospice use for African Americans include preferences for life-sustaining therapies, lack of knowledge about hospice, mistrust of the health care system, and spiritual beliefs.[9–14] Experts and national organizations have identified a role for individual hospice providers in addressing some of these barriers. Recommendations include expanding education and outreach, partnering with African American community organizations such as churches, and employing African American staff.[4–8,15] While there is little data identifying which activities are associated with greater hospice use by African Americans, unexplained variation in hospice use across counties suggests that the practices of individual hospice providers may impact hospice enrollment.[16]

In 1996, A. K. Gordon published findings from a 1990 survey of U.S. hospices examining factors that could affect service to minorities. Over half of the 832 participating hospices reported activities to increase service to African

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Americans, including minority volunteer and staff recruitment and community education.[17] Despite calls from experts and professional organizations for hospices to increase their outreach to African Americans and the availability of resources that provide a guide for doing so, there have been few studies in the last two decades examining hospice provider practices.[5–7,15,18,19] Such data could help to identify best practices to increase hospice use among African Americans. Therefore, the purpose of this study was to examine these practices among hospices in the Carolinas and to identify provider characteristics associated with efforts to increase service to African Americans.

Methods

Design

This study was a cross-sectional survey of North and South Carolina hospices, conducted between December 1, 2009 and September 1, 2010 to examine hospice provider practices to increase hospice use by African Americans. The institutional review board of the Duke University Health System approved this study. Participating hospices received $125.

Study population

We identified eligible hospices using data collected by the Carolinas Center for Hospice and End-of-Life Care, a nonprofit organization committed to the growth of end-of-life care resources and services throughout North and South Carolina. The center houses a data repository of information collected annually by the states' licensure departments. We identified 118 hospices meeting our eligibility criterion, which was in operation for at least three years. Of these, 80 (68%) completed the survey. We extracted the following from the database: agency type (freestanding, home-health affiliated, hospital affiliated); ownership (for-profit, nonprofit, government); average daily census (ADC); and budget size (<1 million, 1 million to <4 million, ≥4 million). We also matched hospice zip codes (for those with more than one office we used zip code of main office) with census data to determine the proportion of African Americans residing in the area where the hospice was located, since this could impact the extent to which hospices participated in activities to increase service to African Americans.[20]

We contacted hospices' executive directors to request their participation in the study and a designee to complete the survey. Of survey respondents, 34% were executive directors and 44% were directors in some other capacity (e.g., compliance, quality, homecare, nursing). The remainder were social workers, chief medical officers, clinical managers, or administrators.

Hospice provider survey

We developed a survey of hospice provider practices to increase service to African Americans based on a review of the literature and guidelines to increase access to health care services for minorities.[5–7,14,15,17–19,21] The survey was reviewed by hospice and palliative care clinicians, researchers, and administrators for face validity and pilot tested in a sample of five hospices outside of the Carolinas. The survey was administered by telephone and the scales included are described below.

Community Education and Outreach Scale and Directed Marketing Strategies Scale

The Community Education and Outreach Scale (CEOS) assessed community education and outreach activities to health care providers and community organizations. Participants were asked, ''In the last two years, in an effort to provide education or outreach to African Americans, has your hospice sponsored programs for or distributed information about hospice care to… (e.g., churches)?'' The Directed Marketing Strategies Scale (DMSS) examined marketing strategies to reach African Americans. Participants were asked, ''In the last two years, has your hospice used marketing strategies such as advertisements or public service announcements to reach African Americans using… (e.g., newspapers)?'' For both scales, hospices reported the frequency of the queried activities using the response scale ''never, rarely, sometimes, often, or always.'' They provided examples and listed activities not queried in the scale. The CEOS included eight items, with a possible score range of 8 to 40; Cronbach's alpha was 0.63, which is in the acceptable range. The DMSS included four items with a possible score range of 4 to 20; Cronbach's alpha was 0.76. Higher scores indicate more frequent community education and outreach activities (CEOS) or directed marketing activities (DMSS).

African American staff

We assessed providers' perceptions about whether there were adequate numbers of African American staff in their organization. They responded, ''too low,'' ''too high,'' ''about right,'' or ''unsure'' after the following statement: ''The number of African American … (e.g., registered nurses) in my hospice is….''

We also developed a six-item scale assessing whether the hospice had tried to recruit African American staff (African American Staff Recruitment Scale). Participants responded from 1 (strongly disagree) to 5 (strongly agree) to the following: ''My hospice has tried to recruit African American … (e.g., registered nurses).'' The possible score range for the scale is 6 to 30, with higher scores indicating greater recruitment efforts; Cronbach's alpha was 0.87. Although we asked about licensed practical nurses (LPNs), this item was not included in the scale, since 40% of hospices did not employ LPNs.

Other items (goals, concerns, cultural diversity training)

The survey included items assessing beliefs about service to African Americans and organizational goals. Participants were asked, ''How concerned is your organization about the proportion of enrollees served by your hospice who are African American?'' They responded using a scale from not at all to extremely concerned. They were also asked whether they had ''organizational goals regarding increasing the number of African Americans served by their hospice.'' Finally, we asked participants whether they offered cultural sensitivity or diversity training for staff (yes or no) and the frequency of such training (open-ended response).

Analysis

We used summary statistics, counts to characterize categorical items, and means with standard deviations to summarize continuous scores on the scales. We used nonparametric

Wilcoxon tests to compare mean scale scores by sample characteristics, and chi square to examine the relationship between categorical variables. We used Spearman correlations to examine the relationship between continuous variables. We reviewed examples of outreach and marketing strategies provided as free text by participants. We report those strategies mentioned by five or more providers. For all analyses, $p < 0.05$ was considered statistically significant. All analyses were performed with statistical software SAS (SAS version 9.4; SAS Institute, Inc., Cary, NC).

Results

Complete data were available for 79 of 80 participating hospices (see Table 1). Among eligible hospices compared to those that did not enroll in the study ($n = 38$), participating hospices were more likely to be nonprofit (77.22% versus 44.83%, $p = 0.001$); had larger ADC (35.44% versus 14.29% with ADC >100; 48.10% versus 71.43% with ADC ≤50; $p = 0.044$); and had larger budgets (48.84% versus 13.79% with budgets ≥$4,000.000; 22.78% versus 48.28% with budgets ≤$1,000,000; $p = 0.004$). There was no difference in agency type, with over half of participating and nonparticipating hospices identifying as freestanding (55.70% versus 58.62%, $p = 0.8$).

The mean proportion of African Americans residing in the zip code where the hospices' main offices were located was 22%, with a range of 0.3% to 59.6% The majority of hospices (82.5%) were at least somewhat concerned about the low proportion of African Americans that they served. Over three-fourths had set goals to increase service to African Americans. Compared to those who had not, hospices reporting that they had set goals were located in zip codes with a higher mean proportion of African Americans (23.71% versus 16.68%, $p = 0.03$).

Table 1. Hospice Provider Characteristics

	n *(%)*
Ownership	
Nonprofit	61 (77.22)
For-profit	18 (22.78)
Agency type	
Freestanding	44 (55.70)
Home health affiliated	18 (22.78)
Hospital affiliated	17 (21.52)
Budget	
<$1,000,000	18 (22.78)
$1,000,000–$3,999,999	24 (30.38)
$≥4,000,000	37 (46.84)
Average daily census	
≤50	38 (48.10)
51–100	13 (16.46)
>100	28 (35.44)
Concerned about low % of African Americans served by their hospice	
Not at all or not very	14 (17.72)
Somewhat	32 (40.51)
Very or extremely	33 (41.77)
Organizational goals to increase number of African Americans served	
Yes	62 (78.48)
No	17 (21.52)

Community Education and Outreach Scale and Directed Marketing Strategies Scale

Hospices reported moderately frequent community education and outreach and somewhat less frequent directed marketing. The mean score on the CEOS was 27.2 (SD 5.2), with a range of 10 to 40 (possible score range 8 to 40); and the mean score on the DMSS was 8.7 (SD 4.2), with a range of 4 to 20 (possible score range 4 to 20). There were no differences in scores on either the CEOS or DMSS by ownership, agency type, budget, ADC, or participants' concern about service to African Americans. However, hospices with goals to increase service to African Americans reported more frequent community education and outreach (mean CEOS scores 28.06 versus 23.94, $p = 0.007$) and directed marketing (mean DMSS scores 9.48 versus 6.05, $p = 0.002$). There was also a positive correlation between the proportion of African Americans in the zip code where the hospices' main office was located and the frequency of directed marketing as measured by DMSS score ($r = 0.23$, $p = 0.04$); this was not true for the CEOS.

Table 2 lists outreach practices. Hospices most commonly reported outreach to churches (92.40%), social service organizations (75.95%), physician's offices (73.42%), and nursing homes (72.15%). The social service organizations included local departments of social services and senior centers. Fewer hospices reported outreach to businesses (40.5%) or civic groups (35%); the most commonly mentioned were barber shops, beauty shops, fraternities, and sororities. Hospices also reported outreach to groups not listed in the survey, such as support groups and those providing caregiver services. The most commonly employed directed marketing strategies included the newspaper (48.1%) and radio (40.5%); 46% reported ''other strategies,'' including providing information at health fairs and community events (see Table 2).

African American staff

The mean score on the African American staff recruitment scale was 22.3 (SD 4.1), with a range of 12 to 30 (possible score range 6 to 30). There were no differences in scale scores by any of the hospice characteristics. Hospices with goals to increase service to African Americans reported greater efforts to recruit African American staff (mean scale score 22.9 versus 20.0, $p = 0.009$).

Table 3 summarizes hospices' perceptions of the number of African American staff in their organization. The largest proportion reported that the number of African American registered nurses (72.5%) was too low, and over half reported that the number of social workers, chaplains, and volunteers was too low. Only the proportion of certified nursing assistants (CNAs) and board members was reported as ''too high'' by a small number of hospices (8.75% and 2.5%, respectively). In general, hospices had tried to recruit African Americans of all disciplines, with the greatest efforts reported for registered nurses.

Cultural diversity or sensitivity training

A majority (89.87%) of hospices reported cultural diversity or sensitivity training for staff. The frequency ranged

Table 2. Community Education/Outreach Practices and Directed Marketing Used by Hospice Providers to Reach African Americans

	Sometimes, often, always in last 2 years, n *(%)*[a]
Community education and outreach practices	
Community organizations	
Churches	73 (92.41)
Social service organizations	60 (75.95)
	Examples (*n*):
	Department of Social Services 31 (39.24)
	Senior centers or services, councils 25 (31.65)
	Free clinics and health department 16 (20.25)
	Meals on Wheels or food resources 12 (15.19)
Businesses	32 (40.5)
	Examples (*n*):
	Barber shops and beauty salons 23 (29.11)
	Funeral homes 8 (27.59)
	Restaurants 7 (8.86)
Civic groups	28 (35.44)
	Examples (*n*):
	Fraternities and sororities 18 (22.78)
	Kiwanis, Rotary, Lion's Club 14 (17.72)
Health care organizations	
Physicians' offices where at least 25% of patients are African American	58 (73.42)
Nursing homes where at least 25% of patients are African American	57 (72.15)
Hospitals where at least 25% of patients are African American	54 (68.35)
Additional sites for community education/outreach not specifically queried in scale	
Other organizations	37 (46.83)
	Examples (*n*):
	Support groups and services—HIV, Parkinson's, Alzheimer's, cancer, grief/bereavement 13 (16.46)
	Caregiver/daycare Services 10 (12.66)
	Women's groups 7 (8.86)
	Colleges 6 (7.59)
	NAACP or other black advocacy groups 6 (7.59)
	United Way 5 (6.33)
Directed marketing strategies	
Newspaper	38 (48.10)
Radio	32 (40.51)
Television	16 (20.25)
Other	36 (45.57)
	Examples (*n*):
	Health fairs 25 (31.64)
	Community events—Martin Luther King holiday, Black History Month, Christmas, parades, festivals, concerts, expos 12 (15.19)
	Billboards, website, brochures, magazine 5 (6.33)

[a]Column represents number and % of participants who responded sometimes, often, or always when asked about community education and outreach strategies or directed marketing to reach African Americans in the last two years to sites listed in first column. These individual items were part of the Community Education and Outreach Scale or Directed Marketing Strategies Scales.

from once upon hire (5.6%) to every quarter (9.86%); most reported annual training (70.4%).

Discussion

In this study we found that most hospice providers were concerned about the low proportion of African Americans that they served, had set goals to increase enrollment of African Americans, and were engaged in efforts to reach African Americans in their service area. These efforts included community education and outreach, most commonly involving churches, social service organizations, physicians, and nursing homes. Less frequently, hospice providers used directed marketing via radio, television, and newspapers. Many hospices also reported efforts to recruit African American staff of all disciplines and rated the proportion of African American staff as too low, with the largest number of hospices reporting this for registered nurses, social workers, chaplains, and volunteers. Almost all hospices conducted cultural sensitivity training for staff. Efforts to reach African Americans did not

Table 3. Hospice Providers' Perceptions of Adequacy of African American Staff and Reports of Attempts to Recruit African American Staff

Number of African American staff in the hospice[a]	*Too low,* n *(%)*	*Too high,* n *(%)*	*About right,* n *(%)*	*Tried to recruit African Americans (agree/strongly agree),* n *(%)*[b]
Registered nurses	58 (72.50)	0	20 (25.00)	51 (63.75)
Licensed practical nurses	24 (30.38)	0	17 (21.50)	22 (27.50)
Certified nursing assistants	15 (18.75)	7 (8.75)	55 (68.75)	44 (55.00)
Social workers	44 (55.00)	0	33 (41.25)	43 (53.75)
Chaplains	44 (55.70)	0	30 (37.97)	32 (40.00)
Volunteers	42 (52.50)	0	33 (41.77)	4 (5.06)
Board members	37 (46.25)	2 (2.50)	28 (35.44)	48 (60.00)

[a]Providers responded to the statement, ''The number of African American staff in my hospice is….'' for all disciplines in column 1 using response scale ''too low,'' ''too high,'' ''about right,'' or ''unsure.''

[b]This column includes individual items from the African American Staff Recruitment Scale. Hospices were read a statement: ''My hospice has tried to recruit African American…'' for the disciplines listed in column 1. *n* and % in column 5 reflect those who agreed or strongly agreed with the statement.

vary significantly by hospice characteristics but were greater among hospices that had set goals to increase service to African Americans. The findings of this study suggest that hospice providers are aware of black-white differences in hospice use and are utilizing a number of strategies to increase service to African Americans.

The Department of Health and Human Services' Office of Minority Health has developed National Standards for Culturally and Linguistically Appropriate Services (CLAS) to advance health equity. CLAS standards provide a set of recommendations for health care organizations to ensure that their services are accessible to and meet the needs of diverse populations. One of the CLAS standards recommends partnering with the community to facilitate awareness and understanding of services and to improve service delivery.[21] This recommendation is especially important for hospice providers, since lack of knowledge of hospice has been cited as a barrier to hospice use for African Americans.[9,12,13] In this study the church was the most commonly identified partner for community education and outreach. This is not surprising, since African Americans report greater religious commitment and more often attend religious services than whites.[22, 23] Additionally, the church has a history of involvement in activities to improve the health of African Americans and is an important source of support for caregivers of seriously ill patients.[24–27] Further, partnerships between hospices and churches may provide an opportunity for clergy to respond to concerns about hospice use related to spiritual beliefs.[23] Although much of the emphasis on health in the African American church has been related to health promotion and disease prevention, the findings of this study suggest that church-based activities to promote quality of care at the end of life may be growing; however, currently, there are few published reports of such initiatives.[28–31]

In addition to the church, hospices reported reaching out to social service organizations, civic groups, and businesses. As with outreach to churches, these efforts provide an opportunity to share information about hospice with large numbers of African Americans who may have a current or future need for services. Because mistrust of the health care system has been cited as a barrier to hospice use, these activities may also be important in building trust with African Americans by partnering with groups with a long-standing community presence. Nearly 30% of hospices reported outreach to barbershops and beauty shops. Studies report the success of programs in these locations in addressing cardiovascular disease risk factors in African Americans.[32–34] However, there are no data on the use of these venues to provide education about end-of-life care. These findings suggest that hospices are using strategies to reach African Americans that have been successful farther upstream in the disease trajectory.

Hospices also reported frequent outreach to health care providers, including physicians, nursing homes, and hospitals. These efforts are important for all patients, since there is variability in knowledge, attitudes, and practices of physicians, and physician characteristics are an important predictor of hospice enrollment.[35,36] Hospitals may be an important source of referrals, since African Americans are more likely to be referred to hospice after a hospital stay.[37] Outreach to nursing homes is also essential given the growing proportion of African Americans residing in nursing homes. In 2012, 13.9% of nursing home residents were African American compared to 9.6% in 1999.[38,39]

The lack of African American staff has been cited as a barrier to hospice use among African Americans. The CLAS standards recommend recruiting a diverse workforce at every level, and many hospices in this study reported efforts to do so.[21] Hospices were more likely to report that the number of African American registered nurses was too low and least likely to report that the number of CNAs was too low. These findings are consistent with the demographics of these professions. African Americans are 12% of the U.S. working age population and are 10% of registered nurses and 33% of nursing aides.[40]

Recommendations to improve care for diverse groups often include cultural sensitivity training.[5,21] Almost 90% of hospice reported such training. Although we have no information about the content of these training programs, there is evidence that cultural competence training improves knowledge, attitudes, and skills of health care providers and may improve patient satisfaction. The extent to which such training impacts health outcomes or reduces disparities, however, is not known.[41]

An interesting finding of this work is that profit status, budget size, agency type, and hospice size were not associated with efforts to increase service to African Americans. Directed marketing was reported more frequently among hospices with a greater proportion of African Americans in the area where the hospice's main office was located. Although we do not have data on how the specific community

education/outreach and directed marketing activities and associated costs varied by hospice characteristics, the results suggest that strategies to reach African Americans are scalable and that some of these activities may be supported with minimal resources. We did find that hospices that had set goals to increase service to African Americans reported more frequent strategies in all areas queried. This highlights the importance of setting measurable goals to guide strategies to reach African Americans or other vulnerable populations.

This work has a number of limitations. The study included a small sample of hospices in North and South Carolina and most were nonprofit. Both states have a higher proportion of African Americans than in the general U.S. population.[20] Therefore, hospices in the Carolinas may be more likely to work to extend service to African Americans than those in areas with fewer African Americans, and findings may differ in a larger sample of for-profit hospices. The data are from hospice staff report only; we do not know the extent to which they reflect actual practices. Also, there were no validated measures for the questions posed in this study. We developed measures which were reviewed by hospice and palliative care clinicians and researchers for face validity; the scales all had acceptable reliability, and we report data on individual item responses. Finally, we have no information about whether the efforts described were associated with an increase in hospice enrollment by African Americans.

Many hospices are engaged in efforts to increase service to African Americans in their communities. These efforts address some of the commonly cited barriers to hospice enrollment, including knowledge of hospice, spiritual beliefs, mistrust in the health care system, and lack of African American staff. Future research should examine whether strategies commonly employed by hospice providers to reach African Americans result in increased use of hospice care and reduced disparities in the quality of end-of-life care.

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