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# Programmatic barriers to providing culturally competent end-of-life care

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## Abstract

*Despite many efforts to increase access to end-of-life care, culturally diverse groups are still not being served. Interviews of 22 hospice and palliative care program directors in one southeastern state indicated that directors overestimated how well programs are doing in meeting the needs of diverse groups but were very interested in implementing cultural diversity training for their staff. Those who were more concerned about such issues had recruited more diverse volunteers into their programs. The presence of diverse staff or volunteers predicted a more diverse patient population. A number of efforts were underway to develop cultural competence and provide culturally competent care. Several directors reported no efforts in this direction, however. Directors described programmatic barriers and resources*

*needed. The authors concluded that directors should provide leadership in their agencies in welcoming diversity. Implications for further research and work within the larger end-of-life care field are discussed.*

*Key words: end-of-life care, palliative care, hospice, cultural competence, diversity, racial minorities*

## Introduction

A large number of studies have indicated that patients from diverse cultural groups are not receiving the same quality or quantity of healthcare as those from the dominant culture.<sup>1-3</sup> These differences have remained consistent over time and have been linked to disparities in health status and mortality rates.<sup>4-6</sup>

The end-of-life care field mirrors the disparities in the healthcare system as a whole. For example, in 2001, only 18 percent of hospice patients<sup>7</sup> represented ethnic or racial minorities, while they represented approximately 28 percent of the total US population.<sup>8</sup>

This problem remains despite federal law designed to prevent it. The Civil Rights Act of 1964 prohibits exclusion from participation in any activity receiving federal assistance

based on race, color, or national origin. The Bureau of Primary Healthcare<sup>9</sup> mandates that health centers should engage in practices that respect and respond to the cultural diversity of the communities and clients served, should develop systems that ensure participation of the diverse cultures in their community, and should hire culturally and linguistically appropriate staff. The US Department of Health and Human Services<sup>10</sup> has established the elimination of racial and ethnic disparities in healthcare as one of two overarching goals in Healthy People 2010.

A number of studies have examined the reasons why the disparities in access to end-of-life care exist between European American and other cultural groups. Barriers are posed by characteristics of the clients themselves and characteristics of the healthcare system. This study focuses on barriers within the healthcare system.

## Barriers within the healthcare system

Although racial and ethnic characteristics of end-of-life care staff have not been reported, unpublished data collected by Reese and Raymer<sup>11</sup> indicated that only 3 percent of hospice

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bereavement coordinators participating in a national survey represented diverse ethnic or racial groups. This lack of diversity may present a barrier to access and utilization of services<sup>12,13</sup> because of language barriers, lack of understanding of cultural differences,<sup>14-16</sup> and fear and mistrust by clients of the European American healthcare system.<sup>17,18</sup>

Unexamined end-of-life care policies and practice methods are perpetuated by the dominant world view of the larger society.<sup>19</sup> Thus, the beliefs and assumptions of the society at large will characterize the communication between professional and client when the professional has not taken steps to become culturally competent. A lack of knowledge of other cultures may lead to policies, practices, and communication styles that screen out diverse groups or cause offense.<sup>12,16,18</sup> Sue and Sue<sup>20</sup> have argued that underutilization of services is often related to culturally insensitive and inappropriate formalized services for culturally diverse groups. Lack of cultural and linguistic competence on the part of healthcare professionals may, in fact, serve to further oppress culturally diverse clients that have already faced biased behavior within the larger society.<sup>19,20</sup>

Barriers to culturally competent care presented by the provider organization may include physical location, degree of formality, amount of paperwork, lack of continuity of care, and bureaucracy.<sup>15</sup> Ineffectual outreach to the community may also create barriers.<sup>21</sup>

A number of barriers also exist in the larger healthcare system. Much has been written about the contribution of Medicare regulations to the problem of access to care.<sup>22</sup> A scarcity of culturally diverse healthcare professionals exacerbates the disparity of cultural backgrounds between staff and clients. Lack of clinician referral sources for minorities may also present a barrier, resulting from lack of access to primary care and possibly

from insufficient education of minority physicians about hospice care.<sup>12</sup> A national survey found, however, that minority physicians have had difficulty getting services for their patients when attempting to make referrals for general healthcare.<sup>23</sup>

### Attempts to address the problem

The National Hospice and Palliative Care Organization (NHPCO) attempted to address this problem by establishing the Task Force on Access to Hospice Care by Minorities in 1987. Its mandate was to review what obstacles prevent minority clients from receiving hospice care and to recommend relevant policy changes to overcome these obstacles. The NHPCO passed the Resolution on Access to Hospice Care in May 1992, which supported the principle of universal access to hospice care for all terminally ill individuals regardless of nationality or creed. In 1994, the Task Force on Access to Hospice Care by Minorities published its report,<sup>15</sup> which included guidelines on development of a task force, outreach activities, and staff diversity training. The Task Force was disbanded several years later. In 2003, the Social Work Section of the National Council of Hospice and Palliative Professionals, which is affiliated with NHPCO, established a cultural competence committee to promote implementation of cultural competence recommendations in the end-of-life care field. In 2004, NHPCO established a new office called Access, Diversity & HIV/AIDS International, which is working to develop a Diversity Toolkit for distribution to all provider members.

In addition, a number of models for developing culturally competent services have been developed.<sup>4,5,24-27</sup> The US Department of Health and Human Services is funding a project to establish cultural competency training for

medical students ([www.woundcare.org/newsvol6n1/ed1.htm](http://www.woundcare.org/newsvol6n1/ed1.htm)). Last Acts, a program of the Robert Wood Johnson Foundation, hosts conferences on diversity issues in end-of-life care ([www.lastacts.org](http://www.lastacts.org)). The National Center for Cultural Competence at Georgetown University was funded to increase the capacity of healthcare and mental health systems to deliver culturally and linguistically competent services.

McPhatter's<sup>28</sup> cultural competence attainment model assumes that achieving competence is developmental, and that learning may take place in the areas of thought, feelings, senses, and behavior. This model comprises three components: 1) grounded knowledge base, which is the analysis and reformulation of the knowledge base using sources of information that include communities of color, traditional and nontraditional institutions, and other disciplines; 2) enlightened consciousness, which is the reordering of world views and shifting of consciousness; and 3) cumulative skill proficiency, which is an ongoing process of skill development in valuing others' world views, accepting and engaging a culturally diverse client population, and using cross-cultural communication skills. Finally, Galambos<sup>19</sup> recommended development of policies and programs that support the use of nontraditional forms of treatment in intervention plans, including the use of informal systems, natural support systems, indigenous health and therapeutic methods, and spiritual dimensions.

Research is lacking on whether general adoption of these methods to increase minority access has occurred. Ahmann<sup>4</sup> reports that healthcare providers are at varying levels of cultural competence, but that few have systematically incorporated culturally competent principles and practices into their program delivery. Kemp<sup>16</sup> has criticized hospice organizations for not making efforts toward community outreach.

How concerned are you about the low percentage of clients in hospice and palliative care that come from diverse cultural groups?									
1	2	3	4	5	6	7	8	9	10
Not at all concerned									Extremely concerned
How well do current hospice and palliative care programs meet the needs of culturally diverse groups?									
1	2	3	4	5	6	7	8	9	10
Not well at all									Extremely well
How interested are you in implementing cultural diversity training for your staff?									
1	2	3	4	5	6	7	8	9	10
Not at all interested									Extremely interested
How interested are you in implementing a community outreach program?									
1	2	3	4	5	6	7	8	9	10
Not at all interested									Extremely interested

**Figure 1. Cultural diversity attitude scale.**

This study attempted to determine the level of concern of hospice and palliative care directors for the disparity in services to diverse groups, as well as their interest in developing the cultural competence of their programs and the barriers they are experiencing in implementing recommendations for culturally competent care. We gathered information in an exploratory study of 22 hospice and palliative care program directors in one southeastern state.

### Methodology

The sample included an exhaustive list of 50 provider members of the state hospice and palliative care organization. Twenty-two directors of these programs agreed to be interviewed, resulting in a 44 percent response rate. The sample included 13 hospice-only programs and nine programs that included both hospice and palliative care programs.

The data were collected in a telephone interview that included both

quantitative and qualitative questions. The quantitative section included a four-item cultural diversity attitude scale<sup>29</sup> (Cronbach's alpha = .81). The scale is shown in Figure 1. The brevity of the scale may limit its reliability (although the Cronbach's alpha obtained for this study is adequate). The scale should be considered an initial attempt to gather information about directors' attitudes.

In addition, the quantitative section recorded the directors' estimates regarding the diversity of patients, staff, and volunteers in the program. It is recognized that these are only estimates. It was not considered feasible to require the director to gather these statistics; instead, we asked for the director's best guess. Future studies should include more accurate diversity statistics. The interview schedule was pretested with several participants before conducting the full study.

### Quantitative results

Table 1 presents mean scores on the

cultural diversity attitude items. Mean scores ranged from 5.29 to 9.09, with a mean total score of 30.67 (SD = 5.27). The lowest mean score was on the directors' knowledge of how well programs are doing in meeting the needs of diverse groups, and the highest mean score was on interest in cultural diversity training for one's staff.

Table 2 shows the mean percent and standard deviation of patients, staff, and volunteers from diverse cultural groups in a program. African-Americans represented the largest minority group (mean = 12.73 percent, SD = 19.87). Directors estimated the second largest minority patient group to be gays and lesbians (mean = .67 percent, SD = 1.31). For both African-Americans and gays and lesbians, directors estimated that, on an average, there were more staff members than patients in these categories. There were also volunteers in both of these groups, though not as many as patients or staff. There were patients in every cultural group included in the study. There were no Jewish, Asian, or

Marshallese staff. There were volunteers in every cultural group except for Marshallese. One participant declined to provide information about cultural diversity in his or her program, stating it was “not applicable” because of the lack of diversity in his or her community.

Table 3 shows significant correlation results for the study. Concern about the low percent of diverse clients served in end-of-life care predicted interest in cultural diversity training and community outreach. The less directors thought that programs met the needs of diverse cultures, the more they were interested in community outreach, and the more they had recruited diverse volunteers into their programs. Directors interested in cultural diversity training tended to be interested in community outreach. The percent of African-American staff predicted the percent of African-American patients, and the percent of gay or lesbian volunteers predicted the percent of gay or lesbian patients.

## Qualitative results

### *Increasing cultural competence of the team*

Efforts in this area included cultural diversity training, individual efforts to increase knowledge, and recruitment of diverse and bilingual staff and volunteers. Methods of providing cultural diversity training included special in-service training for staff and volunteers and adding cultural diversity training to new employee orientation. In some programs, cultural diversity training was offered annually; in others, it was mandatory for all employees. Efforts made by individuals to increase cultural competence included reading the current literature, specifically *The Hospice Journal* and information disseminated by the National Hospice and Palliative Care Organization, seeking information from the Internet, learning Spanish, and learning directly from clients. These individual efforts would especially be

Item	Mean score	Standard deviation
Concern about low percent of diverse clients 1 = Not at all concerned 10 = Extremely concerned	7.09	2.96
How well do you think programs meet needs? (Recorded in reverse) 1 = Extremely well 10 = Not well at all	5.29	1.85
Interest in training 1 = Not at all interested 10 = Extremely interested	9.09	1.60
Interest in outreach 1 = Not at all interested 10 = Extremely interested	8.45	2.09
Total score on scale (possible score of 4 – 40)	30.67	5.27

made after the staff member was assigned the case of a client from a diverse cultural or religious group.

### *Increasing linguistic competence*

Efforts to bridge the language barrier included the use of culturally appropriate written materials and the use of interpreters. The written materials included pamphlets in various languages, including information on spiritual care, patient rights, and Medicare. Spanish display boards were available for use in community outreach efforts. Most information was in Spanish, although one program had materials in Vietnamese.

Nineteen out of 22 programs had interpreters available. Most of these were Spanish interpreters, although one program had German, Polish, and Dutch interpreters. Several programs had a bilingual nurse on staff.

### *Community outreach*

Efforts to reach out to the community included meetings with diverse

community members and public education. Directors had arranged and attended meetings, given presentations, and arranged for speakers. One program had invited a Hispanic community member to the hospice facility to discuss available pain control methods. Public education efforts included health fairs and in-home services fairs particularly aimed at the Hispanic community. Public education and advertising were provided through African-American churches. Also, programs provided flyers in grocery stores and churches, where diverse individuals could be found. One program advertised on a radio station.

### **Barriers to providing culturally competent care**

Several programs had made no effort to provide culturally competent care. One director stated that since their community was not diverse, there was no need to increase the cultural competence of the team or participate in community outreach. One stated that

**Table 2. Mean percent/standard deviation of patients, staff, and volunteers from diverse cultural groups**

Cultural group	Patients		Staff		Volunteers	
	Mean (percent)	SD	Mean (percent)	SD	Mean (percent)	SD
European American	64.77	39.11	63.27	41.30	56.41	43.08
African-American	12.73	19.87	13.19	22.91	11.10	22.15
Gay/lesbian	.67	1.31	1.09	2.58	.41	1.22
Jewish	.43	.90	.00	.00	.05	.22
Hispanic	.41	.72	.91	4.26	.23	.43
Asian	.39	1.09	.00	.00	.23	.53
Marshallese	.05	.22	.00	.00	.00	.00
Middle Eastern	.02	.11	.09	.43	.04	.21
Other cultural groups	.003	.01	.00	.00	.10	.46

Note: Total mean percentages may not add up to 100. Percentages are directors' estimates rather than actual provider records.

although individual efforts to increase cultural competence were encouraged, staff members did not make much effort in that direction. One stated that overcoming the barriers to community outreach was too difficult.

Several directors stated that they were experiencing no barriers to providing culturally competent care. They stated that their staff had had cultural competence training and felt prepared and willing to provide culturally competent care. One stated they had a diverse staff for their area, and one stated they had a bilingual nurse. Others stated that diverse clients' needs were met and they were not lacking in resources.

On the other hand, several directors described barriers to providing culturally competent care, including programmatic barriers, client barriers, government regulations that make it difficult to meet the needs of diverse populations, and the lack of referrals by physicians.

#### *Programmatic barriers*

Barriers within the context of the program itself included language barriers, lack of awareness of cultural diversity issues, a culture within the community and program that was not open to diversity, inability to find information and culturally appropriate materials, and lack of access to and contacts within diverse communities.

Language barriers within the program included the lack of bilingual employees, particularly Spanish-speaking employees. One director stated this problem exists because it is not a prerequisite for employment. Other directors described the lack of access to or difficulty contracting with interpreters. One director said that although they have interpreters available, they don't use them. One program director said they usually depend on the family to interpret.

Two directors said they do not use culturally appropriate written materials, and another didn't know whether

they were used. One director explained that there was a lack of awareness among the staff that these materials were needed. The other stated there was a lack of diversity in the community; thus, culturally appropriate materials were not needed. One director expressed a concern regarding a lack of resources in languages other than Spanish.

Several directors stated a barrier was posed by the staff's lack of awareness of cultural diversity issues, including a lack of knowledge about diverse cultures and religions. They stated that their staff needed information specifically about the Muslim and Buddhist religions. They stated that their staff was not aware of the need for this information—that "they don't know what they need to know."

Several programs spoke of barriers that arose because of a local culture that was not open to cultural diversity. They said that if the local community is not open to outsiders and does not



**Table 3. Significant correlation between study variables**

	Concern about low percent of diverse clients	Estimate of how well programs meet needs (coding reversed)	Interest in cultural diversity training	Percent of African-American patients	Percent of gay/lesbian patients
Interest in cultural diversity training	r = .54 p = .009				
Interest in community outreach	r = .74 p = .000	r = .58 p = .005	r = .66 p = .001		
Percent of African-American staff				r = .96 p = .000	
Percent of gay/lesbian volunteers					r = .48 p = .03
Percent of Hispanic volunteers		r = .59 p = .005			
Percent of Asian volunteers		r = .63 p = .002			
Percent of Middle Eastern volunteers		r = .46 p = .04			

reach out to minorities, the hospice or palliative care program may hire only those from its own culture, and then seek only clients from that same culture. One director stated that racism within the local culture played a part in this. Several directors described a lack of comfort on the part of their staff with diverse clients, including fears regarding differing religions, care for AIDS patients, and therefore care for gay patients.

*Client barriers*

Directors also described barriers experienced by clients that limit access to hospice or palliative care. These included economic factors, lack of trust in the medical profession, need for education about hospice and palliative care, particularly on the part of Hispanic people, difference in religious and cultural beliefs, and language barriers. Hispanic and African-American clients were particularly thought to have a lack of trust. Directors thought some clients were reluctant to access services because of

past negative experiences. One director thought this was the major barrier to providing culturally competent services. Directors related that differences in cultural and religious beliefs posed barriers, including differing views of death, a preference to care for their own families and use their own methods rather than engaging the healthcare system, and a view of inpatient care as a sign of weakness. Difficulty with the English language was again cited as a barrier to access.

*Resources needed to provide culturally competent care*

Several directors described resources needed to provide culturally competent care. These included cultural diversity training and consultants, nurses from diverse populations, educational materials including films and videos, federal policy change, funding, and additional staff.

Training needs mentioned included cultural diversity workshops, especially those provided on site. They stated that this training should include

service approaches for diverse ethnic and religious groups and information about resources available in the community. The need for a diverse staff was mentioned, with one director stating they had tried to recruit a nurse from a diverse cultural group but were unable to attract any applicants. Several directors expressed a need for more time; they stated they had a small staff and this posed a barrier to cultural competence efforts. A need for financial resources was also expressed, with funding needed for culturally appropriate materials, displays, community outreach efforts, and formal workshops.

**Discussion**

This study should be considered an initial exploration of directors' attitudes in one state. The cultural diversity attitude scale is brief and lacks in-depth measurement of all aspects of attitudes about cultural diversity. The estimates of diversity of patients, staff, and volunteers are based on the directors' best guesses and can only

give us a broad outline of trends in the state. The study provides useful new information, however, that can be used as a basis for further research. A strength of the study is its qualitative approach, which provides a greater opportunity for directors to provide unexpected information about the problem.

Consistent with the literature, directors in this study described programmatic barriers including lack of linguistic competence, lack of cultural knowledge of staff, disparity of cultural backgrounds between staff and clients, and difficulties in outreach to the community. They were also aware of the larger system barriers of Medicare regulations and the scarcity of diverse healthcare staff. Other programmatic barriers observed in the literature were not mentioned, however, including physical location of the program, degree of formality, amount of paperwork, lack of continuity of care, bureaucracy, initial personal questioning of clients, and hospice policies inconsistent with patient values. It is not known whether these barriers did not exist in their programs, or whether the directors were not aware of such barriers.

New information was gathered about efforts being made by programs, barriers experienced, and resources needed to provide culturally competent care. We learned that some program directors are quite knowledgeable about barriers experienced by culturally diverse clients. Sensitive and honest feedback was given on the barriers posed by a lack of acceptance of cultural diversity in the community and on the part of staff members.

New information was also gathered about the attitudes of program directors about cultural diversity. On average, directors had very high interest in cultural competence training for their staff. In contrast, some directors did not see a need to provide culturally

competent care based on a lack of diversity in their communities.

The assessment on the part of directors of how well hospice and palliative programs are doing in providing culturally competent care was found to be an important predictor of interest in community outreach to diverse populations. Similarly, concern about the low numbers of culturally diverse clients receiving end-of-life care predicted interest in cultural diversity training, interest in outreach activities, and recruitment of diverse volunteers. Thus, it is of key importance that directors understand the poor record of the end-of-life care field in providing care to diverse clients.

This study also provided estimates about diversity of staff and volunteers and new information about percentages of gay and lesbian patients. It also provided evidence that the existence of diverse staff and volunteers predicts diversity of patients. It is not known, however, whether this relationship is causal—it is possible that diversity of the community in general will predict diversity of staff, volunteers, and patients. Future research is needed to clarify the causality of these relationships and also to collect data that is more reliable than directors' estimates. One interesting finding is that volunteers existed from most of the ethnic groups we investigated. Programs had made better progress in recruiting diverse volunteers than paid staff.

#### *Efforts needed on the part of program directors*

The results of this study suggest that directors should provide leadership in their agencies in welcoming diversity. Davidhizar, Dowd, and Giger<sup>25</sup> suggest that a positive climate in a program must be initiated by the manager, and that actions must be taken such as allocating time for required cultural competence training, establishing goals for

diversity with measurable outcomes, establishing culturally competent approaches to care, and acting as a role model for culturally competent behaviors. They should use formal interpreters rather than family members, since patients are often reluctant to openly reveal information when it must be translated by a family member.<sup>30</sup> They should consider hiring some bilingual staff members—an easier accomplishment if they make efforts to hire staff from diverse groups. Directors and those healthcare administrators responsible for budgeting for hospice and palliative care programs should realize that cultural competence training, culturally competent services, and community outreach are necessities and should allocate the resources necessary to provide them.

#### *Efforts needed within the larger end-of-life care field*

Work is also needed within the larger healthcare system in order to address the barriers identified in this study. Efforts must continue to increase the numbers of culturally diverse professionals entering end-of-life care. In addition, work needs to continue to develop more culturally competent Medicare regulations. Hospice and palliative care directors must be made aware of the lack of access to care for diverse clients, as well as the Healthy People 2010 goal of elimination of racial and ethnic disparities in healthcare. They must be made aware of the need for cultural competence training, culturally appropriate materials, diverse staff and volunteers, community outreach, and the importance of allocating funds for these efforts. On-site training in cultural competence should be provided to their teams. Future research should explore the attitudes and cultural competence of directors and staff as well as progress in providing culturally competent care.



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