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Op-ed

Racial disparities in hospice: moving from analysis to intervention

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Hospice is a program designed to provide comfort—rather than curative—care to terminally ill patients and support to their families. Hospice services are provided by a multidisciplinary team of physicians, nurses, social workers, clergy and volunteers who work together to help patients and their families meet the challenges of end-of-life care. Hospice services can be provided in a variety of venues including the home, inpatient hospice facilities and long-term-care facilities. Several studies have documented the benefits of hospice to patients and their families. For example, in a randomized, controlled trial of terminally ill cancer patients and their primary care givers, Kane et al. found that patients enrolled in a hospice program experienced significantly less depression and expressed more satisfaction with care [1]. Furthermore, caregivers of hospice patients showed somewhat more satisfaction and less anxiety than did those of controls [1]. Bereaved family members told Teno and colleagues in a national study that loved ones who died at home with hospice services had reported fewer unmet needs and greater satisfaction with their experience [2]. Finally, Miller et al. observed that hospice enrollment improves pain assessment and management for nursing home residents [3]. The literature consistently finds that participation in a hospice program improves the quality of care patients receive at the end of life.

Since the inception of the Medicare hospice benefit, hospice services have been available to many patients. Despite these additional sources of funding and the evidence of improved quality of care at the end of life, African Americans and members of other ethnic minority groups consistently underutilize hospice. For example, in a secondary analysis of the 1993 National Mortality Followback Survey, Greiner et al. found that being African American was negatively associated with hospice use regardless of the patient's access to health care [4]. In a retrospective analysis of more than one million Medicare enrollees, Virnig and colleagues found that the rate of hospice use was significantly lower for blacks than for nonblacks [5]. Furthermore, even though blacks made up 12 percent of the population of the United States in 2004 they accounted for only 8.1 percent of hospice admissions for that year [6].

Several possible causes for racial disparity in hospice utilization have been proposed. Research has suggested, for instance, that lack of knowledge about hospice programs is a barrier to their use in the African American community [7]. Mistrust of the

health care system, conflicts between individuals' spiritual and cultural beliefs and the goals of hospice care, and preferences for aggressive life-sustaining therapies have also been suggested as causes [8-12]. Some believe that providers' conscious or unconscious stereotyping of their patients may also lead to disparities in health care [13]. Additionally, the prohibitive cost of health care, barriers to access and a culturally insensitive health care system have been thought to contribute [8]. Few of these reasons for underutilization of hospice services by African Americans and members of other minority and ethnic groups have been studied in depth.

When compared with use by Caucasian patients, not only do African Americans underutilize hospice, they also perceive the quality of end-of-life care differently. According to Welch et al. blacks were less likely to rate the care their family members received at the end of life as "excellent" or "very good." They were more likely to have concerns about being told what to expect when their loved one died and more likely to be distressed about the amount of emotional support they received from the health care team during their loved one's last days [14]. There were, however, marked decreases in the disparities noted in perceptions about the quality of care once patients enrolled in hospice, particularly with regard to overall satisfaction with services and attending to the needs of family members [15]. Hence, there is evidence that having hospice care leads to improvements in African Americans' perceptions of end-of-life care.

Though initiatives have been implemented in some areas, more culturally sensitive education is needed to increase awareness of hospice and its benefits. Some studies suggest that cultural diversity among hospice staff may influence diversity among hospice patients [11]. Consequently, hospice programs should strive to increase diversity not only among their patient populations but also among their employees and volunteers. Given that conflicts between cultural preferences and hospice goals are thought to inhibit its utilization, cultural sensitivity should be emphasized to all health care workers, particularly those who care for patients at the end of life. Interventions directed at these areas are sorely needed, as is evaluation of their effectiveness.

Access to hospice has been increasingly thought of as a public health matter. The right to quality care at the end of life is one that should be extended to everyone regardless of race, ethnic background or socioeconomic status. Barriers to hospice utilization should be researched and identified so that appropriate interventions can be conducted to overcome these obstacles. The evidence that hospice is underutilized by those of underserved communities is substantial, but few steps are being taken to understand and reverse this trend. The time has come for research to move from the analysis of disparities in end-of-life care and hospice utilization to identification of barriers and interventions to reverse the trend.

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