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# The Need for Culturally-Based Palliative Care Programs for African American Patients at End-of-life

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Patients facing life-threatening illness often experience unnecessary and preventable suffering including extreme and prolonged pain, psychological distress, as well as unsatisfactory communication with doctors, all of which result in enormous strain on patients and caregivers (Chochinov et al., 2009; Kamal et al., 2011; Morrison & Meier, 2011). It is common for needs in the physical, psychosocial and spiritual domains to be unmet (Zhukovsky, 2000). As a result, the last few weeks and months of life, and that of their loved ones, may be additionally burdened with physical, emotional and spiritual suffering. Palliative care programs, interdisciplinary care focused on relief of pain and other symptoms in support of best possible quality of life for patients with serious illness and their families, or consultations with palliative care experts where such team programs are not available, have been shown to reduce symptoms, alleviate suffering, improve doctor-patient communication and satisfaction with care, improve family satisfaction, and enhance the efficiency and effectiveness of hospital services (Bakitas et al., 2009a; Bakitas et al., 2009b; Casarett et al., 2008; Lagman, Rivera, Walsh, LeGrand, & Davis, 2007; Morrison & Meier, 2011; O'Hara et al., 2010), as well as to be associated with hospital cost savings (Morrison et al., 2008; Morrison et al., 2011; Penrod et al., 2010). Palliative care consultations for inpatients have successfully identified unrecognized symptoms and unmet problems (Abraham, Callahan, Rossetti, & Pierre, 1996; Bailey et al., 2005; Bascom, 1997; Kuin et al., 2004; Manfredi et al., 2000), and have been associated with lower use of ICUs (Elsayem et al., 2006; Norton et al., 2007), lower likelihood of dying in ICU (Elsayem et al., 2006), lower costs of care (Penrod et al., 2006; Smith et al., 2003), and improvement in care processes, including medication prescribing and documenting patient goals for care (Bailey et al., 2005; Higginson et al., 2002; Higginson et al., 2003).

Despite palliative care's proven effectiveness, numerous studies have shown that African Americans underutilize palliative care and/or hospice services (Cohen, 2008; Colon & Lyke, 2003; LoPresti, Dement, & Gold, 2016; Ludke & Smucker, 2007; Payne, 2016; Rhodes, Teno, & Welch, 2006). Three reasons have been suggested: (i) A lack of exposure to information about hospice or palliative care (Johnson, Kuchibhatla, & Tulsky, 2009), leading to a lack of awareness of these options (Hazin & Giles, 2011; Wicher & Meeker, 2012). (ii) Values of End-of-life care practiced in the US may not be ones that hold the same reference for African Americans. Historically end-of-life care in U.S. has been rooted in values that represent the cultural and religious values of the white middle class

(Krakauer, Crenner, & Fox, 2002; Wicher & Meeker, 2012). What is perceived and promoted as advantageous to one group may not hold the same beneficial value to another group with a different frame of reference, value system and life experience (Baker, 2000). Two mainstream elements not consistent with African Americans include: a. An emphasis on individual choice, which conflicts with African American values that are more family-centered in decision-making, especially for life transitions (Mazanec, Daly, & Townsend, 2010). The importance of faith, spiritual beliefs and the church are key components for many African Americans (Wicher & Meeker, 2012). b. Spiritual beliefs are important in understanding and coping with illness, and provide a framework within which treatment decisions are made (Johnson, Elbert-Avila, & Tulsy, 2005; True et al., 2005), yet a recent study (Ernecoff, Curlin, Buddadhumaruk, & White, 2015) found physicians rarely asked patients about their spirituality. The concept of hope is a central tenet in the African American church (Kennard, 2016), and faith in God's healing power is encompassing (Mansfield, Mitchell, & King, 2002). This is often at odds with the sharing of a terminal prognosis by physicians (Payne, 2016). The African American church has long been a constant source of empowerment, social change and support (Mazanec et al., 2010), with pastors playing a key role in end-of-life care; however, only a few end-of-life programs consult with local pastors. (iii) Historical and social factors including slavery, racism, a legacy of medical experimentation and exploitation (Halloway, 2016; Payne, 2016), and ongoing racism and microaggression (Sue, 2010), have left a deep-seated legacy of mistrust in the African American community (Freeman & Payne, 2000; Shrank et al., 2005; Taxis, 2006). A recent report on race and inequality (Goldberg, 2016) found that in the US, African Americans and Whites are "worlds apart" in terms of perceptions of race (e.g., racial equality) and in reality (e.g., racial gap in household income). This is even more strongly felt in the six states of the "Deep South" because those states promoted slavery and had cotton as a major economic source prior to the American Civil War (Webster Dictionary.org, 2016). Another recent study (Sewell, 2015) found African Americans are more likely to believe physicians don't care about them as individuals, and are less likely to trust the judgment and personal competence of the treating physician. Patient-physician communication at end-of-life encompasses active listening to the patient and family, considering all aspects of the patient in a respectful manner, and creating a relationship based on trust and respect (Mack et al., 2009).

In an effort to bring light to the issue and to focus on bringing about health equity at end-of-life for African Americans, a special issue on *Palliative and End-of-life Care for African Americans*, was published (Elk,

2016). In addition to peer-reviewed research articles, African American leaders in the field were invited to write editorials. Although each of their papers had a diverse area of focus, Drs. Payne and Halloway and Pastor Corey all emphasized one overriding message; the need for healthcare providers to acknowledge and respect “the pernicious effects of past and present racism” (Payne, 2016), anticipating that “African American patients may have had experiences of being treated with inequity, disrespect and disregard” (Halloway, 2016), and recognizing that there are “...many despairs that can be experienced in a society that does not always see “all men as created equal” (Kennard, 2016). The editorial, “*The First Step is Recognizing, Acknowledging and Respecting the Inequity, Disrespect and Disregard Our African American Patients Have Experienced,*” emphasizes this as the first step in the process of achieving health equity for African Americans at end-of-life (Elk, 2016).

The second necessary step is for healthcare professionals to gain an in-depth understanding the culture of the particular group of African American patients we serve. Culture is a multi-level, multi-dimensional system that includes beliefs, attitudes, explanations, and practices that ascribe meaning to life events, particularly unexpected and uncontrollable events (Kagawa-Singer, Dressler, George, & Elwood, 2015). Culture fundamentally shapes how individuals make meaning out of illness, suffering, and dying (Kagawa-Singer & Blackhall, 2001). It also strongly influences people’s responses to diagnosis, illness and treatment preferences (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Kagawa-Singer & Blackhall, 2001; Searight & Gafford, 2005). Therefore, in providing palliative care, consideration of the patient and their family’s culture is essential. Lack of sensitivity to, and lack respect for cultural differences may compromise end-of-life care for minority patients (Krakauer et al., 2002). Yet, culturally appropriate models of care that take into consideration the diverse cultural preferences of terminally ill rural patients and their family caregivers are not currently available in the U.S. We echo the need for research on the unique needs of diverse populations, and consideration of varying cultural considerations in end-of-life care expressed by so many (Association of American Medical Colleges et al., 2015; Bakitas et al., 2009a; Elliott, Alexander, Mescher, Mohan, & Barnato, 2016; Higginson et al., 2002; Lamont & Siegler, 2000; Mack et al., 2012; Sewell, 2015). The need to ensure culturally competent, high-quality end-of-life care for diverse Americans is not only a national priority, but has also been expressed as the largest US public health crisis (Periyakoil, Neri, & Kraemer, 2016). A proven effective method to conduct such research is by implementing community-based participatory research (CBPR), a collaborative approach

between academia and community members or organizations, in which community participation is an integral part of the process (from program inception to data interpretation). This method has been widely used in the last ten to fifteen years to address health disparities (Chau, Islam, Tandon, Ho-Asjoe, & Rey, 2007; Wallerstein & Duran, 2006). CBPR has been found to demonstrate positive health outcomes (Laveaux & Christopher, 2009), and to be extremely effective in both development and implementation of projects (Salimi et al., 2012). CBPR principles include recognizing the community as a unit of identity, building on the community strengths, collaborating with community partners at all phases of the research, integrating knowledge and action for the mutual benefit of all the partners involved in the process, and disseminating findings and knowledge gained to all partners (Israel, Eng, Schulz, Parker, & Satcher, 2005). Community input has been demonstrated to enhance both the quality and acceptability of interventions (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007). By using CBPR communities are respected, empowered, have ownership of the project, and make it their own.

It is recognized that research takes many years. Until we have the evidence-base that research provides, there are steps that palliative care programs can take immediately, over and above the first step so strongly emphasized above. This includes recognizing the importance of the church, spirituality and the concept of everlasting hope among African American patients and family, and including African American pastors as part of the program. Making time to get to know the patient and family, asking them what is important and relevant to them is a simple step, as is respecting the stated wishes and preferences, even if these don't conform to usual practice or care. By following these few steps indicated here, we can begin to lay down new paths so necessary to create health equity for all at end of life.

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