In recent years, the Medicare Payment Advisory Commission (MedPAC) has put a degree of emphasis on the long lengths of stay of patients in hospice care. In its March 2013 Report to Congress, MedPAC notes that “between 2000 and 2011, hospice length of stay at the 90th percentile grew substantially, increasing from 141 to 241 days.” However, MedPAC also notes that in 2010 and 2011, 25% of hospice stays were only 5 days or less. While MedPAC suggests that longer lengths of stay raise program integrity questions, and NHPCO has stated that all hospices should be held accountable to the same standards, NHPCO is more so concerned about the higher percentage of patients spending one week or less in hospice care. These patients and their families do not have the opportunity to experience the wide range of benefits during such a short time. Before looking to solutions on how to correct this problem, NHPCO conducted a review of recent literature on why some patients receive hospice care for only a few days.

Three major themes on why patients to do not enter hospice care earlier emerged from the research. The first of these focuses on the decision-making of hospice-eligible patients. As Deborah P. Waldrop notes in her 2006 article in The Gerontologist, selecting hospice care requires changing perspective on one’s prognosis and mortality. Waldrop states that “integrating emotional, psychosocial, and cognitive factors...can cause resistance to the transition” to hospice care. In fact, patients’ knowledge of possessing a terminal diagnosis linked to deferred hospice admission for half of the patients in the study. In a 2005 study published in the Journal of Pain and Symptom Management, researchers found that the most common barriers to a timely referral to hospice are patient and family readiness and the acceptance of the end-of-life. Authors suggest that earlier interventions in the pre-terminal stages of illness, including advance care planning, may lay the groundwork for more successful and earlier referrals to hospice.

Another aspect of late referrals (or late accepted referrals) to hospice relates to racial and ethnic differences among hospice-eligible patients. In the same 2005 Journal of Pain and Symptom Management article, the authors assert that the underutilization of hospice among low-income, urban Hispanic/Latino and African American families may, in part, be due to cultural beliefs of familial provision of care to the dying. African Americans are less likely have primary care visits and, therefore tend to be diagnosed in the later stages of illness. Additionally, fewer primary care visits result in fewer opportunities to discuss prognosis and advance care planning, including the option of hospice.

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study noted that African Americans are more likely than Caucasians to receive care in a hospital or emergency department setting in the two days before hospice enrollment. African Americans are also more likely to desire life-sustaining care at the end of life, have higher cardiopulmonary resuscitation (CPR), and in-hospital deaths.\(^8\)\(^9\) Another study notes that non-white patients are more likely to disenroll from hospice than Caucasians, and more nonwhites disenroll from hospice to pursue more aggressive treatment.\(^10\) Additional barriers to hospice enrollment among African American patients include spiritual beliefs that may conflict with the goals of hospice and palliative care, as well as a lack of minority employees in hospice settings.\(^11\)

A second factor relating to the time at which patients are referred to hospice care is the patient’s diagnosis and/or location of care prior to referral. Waldrop and Mary Ann Meeker highlight in a 2012 study that advanced cancer presents a functional decline and increasing levels of pain and debility, which can be eased under hospice care. However, patients with advanced chronic illness experience “symptom exacerbation” with accompanying hospitalizations, leaving the benefits of hospice care in doubt.\(^12\) The variable disease trajectories create uncertainty regarding a patient’s hospice eligibility, and may lead to late referrals. Waldrop and Meeker suggest that physician-patient communication regarding disease-specific information throughout the course of an illness, not just when treatment ends, is an important tool to facilitate end-of-life decision-making.\(^13\) The perception or recognition of nursing home residents’ declines or uncertain prognoses influenced the decisions of nursing home staff to refer patients to hospice care.\(^14\) One study shows that, when nursing home staff discussed hospice care as an option with patients, and who believed that hospice complemented nursing home care, residents saw longer lengths of service with hospice.\(^15\) Increased communication to physicians and health professionals about hospice care and the services hospices provide is needed, in addition to continued education on the differences in how disease trajectories are expressed in different populations.

A third theme that emerges from the literature on hospice referrals is the fundamental role of the physician. E. Kiernan McGorty and Brian H. Bornstein note that physicians are the primary sources of hospice referrals and are the “gatekeepers” to information on hospice care.\(^16\) McGorty and Bornstein cite a 1999 study that found that physicians tend to delay the discussion of hospice with patients “until

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[the physicians] thought their patients were prepared to accept such options.” Additional barriers physicians have reported regarding referrals to hospice include a lack of knowledge of hospice admissions and election criteria, family dynamics, and insufficient hospice program marketing. Additional reasons physicians can be hesitant to refer patients to hospice include their own perceptions of hospice and difficulty prognosticating a life expectancy.

Similarly, John M. Thomas, John R. O’Leary, and Terri R. Fried examined the relationship between physicians’ discussions of hospice with patients and actual hospice use. Study results show that the difficulty in prognostication is the most significant barrier to discussing hospice with patients. When physicians were more confident with estimating a patient’s life expectancy, the physicians were more likely to discuss hospice options.