

# Hospice Patients in Clinical Cancer Treatment Trials

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A great deal has been written about the ethical dilemma of decision making between hospice and clinical trial participation for patients with cancer (Daugherty & Steensma, 2003; Lynn, 2001). Without available curative treatments, practitioners and patients struggle with the decision of forgoing further clinical trial treatments for hospice care (McGorty & Bornstein, 2003). What if patients did not need to choose between hospice and clinical trial participation and could reap the potential benefits of both?

## Definition of Hospice

The Hospice Foundation of America (2005) defined hospice as comfort and supportive care given to patients and their loved ones when illness does not respond to treatments that have curative intent. Hospice care is provided through a team approach, coordinating care among physicians, nurses, home health aides, physical therapists, social workers, other healthcare professionals, volunteers, friends, and family. Hospice provides physical care to patients and emotional, social, and spiritual care to patients and families during patients' final days. The goal is to offer patients death that includes dignity and comfort (Hospice Foundation of America; National Hospice and Palliative Care Organization, n.d.b).

## Hospice Eligibility and Reimbursement

In 1982, Congress passed legislation mandating that Medicare reimburse hospice

Patients with cancer and practitioners face a conflict when no known curative treatments exist because Medicare and other insurers do not allow clinical trial participation and hospice care to occur concurrently. Patients may not fully benefit from hospice care because of late enrollment. Barriers to hospice referrals exist in the form of clinician attitudes and insurance limitations. Patients with advanced cancer may be prevented from enrolling in clinical trials, and trial participation may limit hospice care. Factors related to this situation are discussed.

costs for eligible patients. Other forms of third-party payers, such as Medicaid, private insurance plans, and health maintenance organizations, also may provide hospice benefits and generally follow the Medicare guidelines for reimbursement (National Hospice and Palliative Care Organization, n.d.a). However, some private plans do not offer the benefit. The eligibility requirement is based on a life expectancy of six months or less from an incurable disease as documented by two physicians; patients are to receive comfort care rather than expensive, curative therapies (Ferrera-Reid, 2004; Meghani, 2004).

In 2002, an estimated 885,000 patients in the United States received hospice care, accounting for approximately 37 of every 100 deaths (Ferrera-Reid, 2004). The National Hospice and Palliative Care Organization (n.d.a) estimated that approximately 950,000 patients in the United States were enrolled in hospice in 2003, an increase of almost 7.5% in one year.

More significantly, studies have demonstrated that as many as 12% of eligible patients are in hospice (Weggel, 1999). A small study interviewing 97 physicians

found that when the physicians offered hospice to eligible patients, 63% accepted the care (Weggel). The statistics raise several key questions. When do physicians begin hospice discussions? If nearly two of every three patients accept hospice, why are so few eligible patients receiving the care? What factors lead patients to decline hospice?

When reviewing specific age populations or specific diseases, most of the more readily attained data are based on older

adults and use Medicare facts and figures. A study looking at older adults receiving Medicare in 1996 found that approximately 43 of 100 cancer deaths occurred while the patients were in hospice (Virnig, McBean, Kind, & Dholakia, 2002). Other researchers have quoted ranges as wide as 20%–51% of eligible patients with cancer enrolling in hospice (Daugherty & Steensma, 2003; Tang, 2003). In 2002, approximately 60% of all cancer deaths in the United Kingdom occurred in hospice, whereas about 42% in the United States occurred in hospice (McGorty & Bornstein, 2003). Differences in reimbursement methods and healthcare models may account for the disparity, but it should be examined further. Hospice involvement in 100% of cancer deaths is impossible, but a goal should be set higher than 42% involvement to promote benefits for more patients with cancer.

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