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# CASE STUDY

## Families and Patients Referred Too Late to Hospice Experience More Unmet Needs

*Families who felt their dying loved ones were referred “too late” to hospice care reported more unmet needs and lower satisfaction with the quality of care provided at the end of life. One out of ten families (11.4 percent) indicated that hospice care was not provided soon enough according to research published in the Journal of Pain and Symptom Management.*

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Inadequate symptom management, poor care coordination, and insufficient emotional support were some of the problems associated with late referrals.

Researchers with the National Hospice and Palliative Care Organization and The Warren Alpert Medical School of Brown University, Center for Gerontology and Health Care Research were somewhat surprised to find that it was not the length of hospice service a dying person received but perceived late referrals to hospice that had a greater effect on the quality of care reported by family caregivers.

“While the majority of families felt their loved one was referred to hospice at the right time, those who thought they got hospice care too late reported greater concerns and more problems with care,” said Stephen Connor, NHPCO vice president for research and one of the authors of the study. “The better we can understand referral patterns and factors that influence hospice admissions, the more successful we will be at getting hospice care to patients and families at the optimal time.”

Timely referrals ensure that patients and families can experience the wide

range of available services and benefits hospices can provide. Hospice provides symptom control, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Family members also receive support, caregiver training, and help coping with the loss of their loved one.

Experts agree that hospice is most beneficial when provided for at least three months. NHPCO reports that the median length of service was 26 days in 2005 with 30 percent of people served by hospice in the U.S. dying in seven days or less. Furthermore, while eight out of 10 Americans have indicated they would prefer to spend their final days at home, those who received hospice for seven days or less were more likely to be cared for outside of their homes.

“In many cases, families aren't aware of what they are missing and don't realize how hospice can make a world of difference for the comfort and quality of life for their loved ones,” added Connor. “One of the most common complaints hospice providers hear from families following the death of a loved one is ‘why didn't we get hospice care sooner?’”

The study, “Timing of Referral to Hospice and Quality of Care,” was based on data collected through the Family Evaluation of Hospice Care, an Internet based repository containing more than 250,000 surveys from families collected from nearly 1,000 hospice programs over the past two years. Developed by Brown and NHPCO, the Family Evaluation of Hospice Care lets researchers look at the relationship of length of stay, perceived timing of hospice referral, and quality of end-of-life care.

Additional research published in JPSM earlier this year found that hospice patients lived longer on average than patients who opted for more conventional care. Efforts to help patients, family caregivers, and other health care professionals understand the value of hospice care are needed.

NHPCO is working to provide information to health care professionals and members of the general public. More than five million Internet visitors have downloaded information from their consumer-focused Web site, [www.caringinfo.org](http://www.caringinfo.org) or called the HelpLine at 800-658-8898.

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The research team included Joan Teno and Janet Shu of The Warren Alpert Medical School of Brown University, Ramona Rhodes of Rhode Island Hospital, David Casarett of the University of Pennsylvania School of Medicine, and Carol Spence and Stephen Connor of the National Hospice and Palliative Care Organization. This research was funded by The Robert Wood Johnson Foundation and the Alzheimer's Association.

### **How do we know if a patient is Hospice appropriate?**

The National Hospice & Palliative Care Organization has published Guidelines for Prognosis in Non-Cancer Diseases. We use these to help primary care physicians and specialists manage patients with end-stage heart, lung, Alzheimer's, and other non-malignant conditions. For a copy, please call (716) 989-2009.

### **Can I bill Medicare or commercial insurance for services once my patients are referred to Hospice?**

Yes, you can. Primary attending physicians continue to bill Medicare Part B and other carriers for the patient's regular office visits or for all covered services. New billing codes are also available for care plan oversight, so reimbursement can be obtained for telephone calls to nurses, as well as patients.

### **Do commercial insurance plans have Hospice benefits?**

Most third-party payers now have a Hospice benefit, similar to the Hospice Medicare Benefit.

### **Do you offer a Hospice evaluation service?**

Yes. Hospice Buffalo staff are available to meet with you, evaluate, and educate patients and families who you believe are appropriate for Hospice services. *There is no fee for this service.* If, during the evaluation, your patient chooses Hospice care and you approve this decision, admission to the program can start right away. Contact Hospice Buffalo Admissions Department at (716) 686-8000.

## **HOW HOSPICE CAN HELP YOUR PRACTICE**

### ***Answers to Questions Physicians Often Ask About Hospice Care***

*Most Physicians know that Hospice is designed to help terminally ill patients and their families with relief from pain and other symptoms. But here are answers to questions physicians often ask about Hospice care and how it can help busy physicians and their office staff cope with the demanding problems seriously ill patients can present.*

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- Coping with Grief and Loss (Life Transitions Center)