

ASHP Statement on the Pharmacist's Role in Hospice and Palliative Care

Position

The American Society of Health-System Pharmacists (ASHP) believes that pharmacists have a pivotal role in the provision of hospice and palliative care and that pharmacists should be integral members of all hospice interdisciplinary teams. Pharmacists practicing in U.S. health systems have been active in defining and providing palliative care since the introduction of hospice through a demonstration project supported by the National Cancer Institute and conducted in New Haven, Connecticut, between 1974 and 1977.¹

Palliative care has been defined by the World Health Organization (WHO) as “the active total care of patients whose disease is not responsive to curative treatment.”² WHO notes that control of pain, other symptoms, and psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

Pharmaceutical care is defined as the direct, responsible provision of medication-related care for the purpose of achieving definite outcomes that improve a patient's quality of life.³ Medication therapy is the cornerstone of most—but not all—symptom control in palliative care. The goals of palliative care and pharmaceutical care are consistent, with the latter being a necessary component of good palliative care.

Hospice is a philosophy and program that delivers palliative care. Hospice care is provided by an interdisciplinary team, which provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's wishes. Emotional and spiritual support are also extended to the family of the patient. In U.S. hospice programs, care is usually provided in the patient's home or in a home-like setting operated by a hospice program. Hospice and palliative care share the same core values and philosophies.

The purpose of this statement is to describe pharmacist's responsibilities and to promote understanding of the various ways in which pharmacists provide or contribute to the provision of care to patients who might be nearing the end of life.

Background

Currently, there are over 3100 operational or planned hospice programs in the 50 states, the District of Columbia, Puerto Rico, and Guam.⁴ According to the National Hospice and Palliative Care Organization, 42% of hospices were free-standing in 2000 and 33% were affiliated with hospitals, 22% with home health agencies, and 9% with hospital systems. Over 700,000 patients were served in 2000, and that number is growing annually. In that same year, 73% of hospices were nonprofit, 20% were for-profit institutions, and 7% were run by government.

In 2000, 2.4 million Americans died from all causes. Hospices admitted approximately 700,000 patients. Of those, 600,000 died while under hospice care. Patients are discharged from hospices typically because of stabilization of disease, moving to an area or facility not served by a hospice, and patient and family preference. Over half of patients who die of

cancer in the United States are cared for by a hospice. Hospices across the country are caring for increasing numbers of patients with cardiac disease, AIDS, renal disease, end-stage pulmonary disease, dementia, amyotrophic lateral sclerosis, Parkinson's disease, and other degenerative neurologic diseases.

Hospice care is covered by Medicare Part A, private health insurance, and Medicaid in most states for patients who meet certain criteria. Any Medicare beneficiary who has a terminal illness with a prognosis of less than six months is, if the disease runs its normal course as certified by the attending physician and the hospice medical director, eligible for the hospice Medicare benefit.⁵ Ninety-one percent of U.S. hospices have met Medicare certification requirements to provide this benefit to Medicare beneficiaries at no cost to the beneficiaries. Many hospices receive charitable contributions to cover the cost of care for terminally ill patients who cannot afford to pay for their care.

Palliative care should be provided in conjunction with curative care at the time of diagnosis of a potentially terminal illness. Palliative care alone may be indicated when attempts at a cure are judged to be futile. Admissions to hospice and palliative care programs often come too late for optimal services to be provided.⁶ The mean length of stay is 50 days, and the median is 25 days.⁴ Many hospice patients die within days to a week after admission to a program.

A nationwide Gallup survey conducted in 1996 indicated that 9 out of 10 adults, if terminally ill and with six months or less to live, would prefer to be cared for at home. A majority of adults would be interested in a comprehensive program of care, such as hospice. When asked to name their greatest fear associated with death, most respondents cited being a burden to family and friends. Pain was the second most common fear. Effective hospice programs address these concerns.

Pharmaceutical services provided by pharmacists in U.S. hospices were surveyed qualitatively and quantitatively in 1979 and 1991.^{7,8}

While many pharmacists continue to serve hospice programs as volunteer consultants to the interdisciplinary team, a growing number of those who work with hospice programs are now considered integral staff and are paid for their services. Inhouse pharmacies have increased since the mid-1990s, and the number continues to grow. A hospice that can support its own pharmacy typically has an average daily census of 200 patients. Most pharmacists who provide pharmaceutical services to hospice programs are not employed directly by the hospices but by a provider of pharmaceutical services, such as a home health pharmacy or hospital. Many are employees of pharmacies that have contracts with hospices to provide drug products and services. In recent years, specialized hospice pharmacy services have been developed in several parts of the United States, and such programs are growing rapidly.

The Hospice Interdisciplinary Team. According to Medicare hospice regulations, a hospice interdisciplinary team should include a doctor of medicine or osteopathy, a registered nurse, a social worker, and a pastoral or other counselor.

Many other professionals and support persons often serve on such teams. In addition, Medicare regulations state that the hospice must “employ a licensed pharmacist; or have a formal agreement with a licensed pharmacist to advise the hospice on ordering, storage, administration, disposal, and recordkeeping of drugs and biologicals.” According to the two published surveys of pharmacist activities in hospices, the hospice pharmacist typically is a full member of the interdisciplinary team.^{7,8}

By regulation, a patient’s plan of care must be reviewed and updated at specified intervals. If a hospice has more than one team, then it must designate the team by which a particular patient will be cared for. Hospice teams typically meet for one or two hours two to four times a month to review patients’ care, status, and needs. Treatment plan modifications, determinations of need for additional services, and planning for consultations with specialists, changes in care settings, imminent death, and other important events are discussed. Education and training are often provided at these meetings as well.

The hospice medical director is a doctor of medicine or osteopathy who is responsible for the medical component of the patient’s care. The director also serves as a consultant to the patient’s primary care physicians and the hospice program staff. Pharmacists coordinate pharmacotherapy by making recommendations for appropriate therapy, educating patients and the hospice team about medications, monitoring therapeutic responses, and performing other medication-related functions. Adjusting drug therapy in accordance with treatment algorithms is a new role for pharmacists in some hospice and palliative care settings.

A registered nurse coordinates the implementation of each patient’s plan of care. After certified nursing assistants, who may provide personal care on a daily basis, nurses make the largest number of home visits. Social workers are responsible for the psychosocial care of patients and their families, and they arrange bereavement care for families after patients die. The volunteer director recruits, trains, and coordinates volunteers—another essential component of hospice care. Volunteers provide needed relief for family caregivers and a broad range of services to patients and their families.

Chaplains address spiritual and existential issues. Hospice chaplaincy is typically nondenominational and is often provided in coordination with patients’ own clergy. Other frequent participants in team meetings include nursing assistants, home health aides, dietitians, physical therapists, occupational therapists, speech therapists, and hospice administrative personnel. Students and postgraduate trainees from a variety of professions, including pharmacy, often attend as well.

Value of the Pharmacist’s Care. Most hospice and palliative care is reimbursed through a capitation plan. Therefore, fees for service generally do not apply. Pharmacists can improve the cost-effectiveness of pharmacotherapy for symptom control in hospice care through patient-specific monitoring for drug therapy outcomes, recommending alternative drug products and dosage forms, minimizing duplicative and interacting medications, compounding medications extemporaneously, improving drug storage and transportation, and educating staff, patients, and families about the most efficient ways of handling and using medications. Systems for documenting these activities and determining cost-effectiveness and the cost–benefit and cost–utility ratios of medications used in the care of terminally ill patients are needed.

Avoidance of admissions to hospitals or long-term-care facilities through improved symptom control is a highly desirable and cost-effective outcome of pharmaceutical care for hospice and palliative care patients.

The Pharmacist’s Responsibilities

High-quality hospice and palliative care requires both traditional and expanded pharmacist activities, including a variety of clinical, educational, administrative, and support responsibilities:

1. *Assessing the appropriateness of medication orders and ensuring the timely provision of effective medications for symptom control.* Pharmacists maintain patient medication profiles and monitor all prescription and nonprescription medication use for safety and effectiveness. Pharmacists provide patients with essential medications within a time frame that ensures continuous symptom control (especially pain relief) and avoids the need for emergency medical services.
2. *Counseling and educating the hospice team about medication therapy.* Pharmacists attend hospice team meetings to advise other team members about medication therapy, including dosage forms, routes of administration, costs, and availability of various drug products. This is done through regularly scheduled educational sessions. Pharmacists develop and maintain a library of contemporary references about medications, dietary supplements, and alternative and complementary therapies. Pharmacists advise members of the hospice team about the potential for toxicity from and interactions with dietary supplements and alternative and complementary therapies.
3. *Ensuring that patients and caregivers understand and follow the directions provided with medications.* Pharmacists ensure that all medication labeling is complete and understandable by patients and their caregivers. Hospice pharmacists communicate with patients, either through the team or in person, about the importance of adhering to the prescribed drug regimen. Pharmacists explain the differences among addiction, dependence, and tolerance and dispel patient and caregiver misconceptions about addiction to opiate agonists. Pharmacists ensure the availability of devices and equipment to permit accurate measurement of liquid dosage forms by patients and their caregivers. Pharmacists counsel patients about the role and potential toxicity of alternative and complementary therapies. When needed, hospice pharmacists visit patients’ homes to communicate directly with patients and their caregivers and to make necessary assessments.
4. *Providing efficient mechanisms for extemporaneous compounding of nonstandard dosage forms.* Hospice pharmacists communicate with pharmaceutical manufacturers to determine the availability of nonstandard dosage forms. Medication-compounding needs in hospice care include the preparation of dosage forms to ease administration (e.g., concentrated sublingual solutions, topical medications), flavoring medications to promote compliance, eliminating or adjusting ingredients that patients cannot tolerate, and preparing or changing drug concentrations. Whenever possible, pharmacists compound formulations for which stability and bioavailability data are available.

5. *Addressing financial concerns.* Hospice benefits usually cover medications. However, patients may lack insurance coverage or benefits may not cover medications that are not considered strictly palliative. Pharmacists communicate with pharmaceutical manufacturers to obtain medications through patient assistance programs.
6. *Ensuring safe and legal disposal of all medications after death.* Medications dispensed to patients are “owned” by the patients and, in most states, cannot be used for other patients. Medications remaining in patients’ homes fall under a variety of hazard categories. Pharmacists are able to assist families with the removal of the medications from the home in compliance with federal and state drug control and environmental protection laws and regulations.
7. *Establishing and maintaining effective communication with regulatory and licensing agencies.* Because hospice patients often require large quantities of controlled substances, open communication with both state and federal controlled-substance agencies is important. Pharmacists ensure compliance with laws and regulations pertaining to medications.

Pharmacists’ Scope of Practice

The pharmacist may have a range of practice privileges that vary in their level of authority and responsibility. Pharmacists who participate in hospice and palliative care should meet the health care organization’s competency requirements to ensure that they provide appropriate quality and continuity of patient care. They should demonstrate required knowledge and skills, which may be obtained through practice-intensive continuing education and pharmacy practice and specialty residencies.

The specific practice of pharmacists should be defined within a scope-of-practice document or a similar tool or protocol developed by the health care organization. The scope-of-practice document defines activities that pharmacists would provide within the context of collaborative practice as a member of the interdisciplinary team, as well as limitations where appropriate. The document should indicate referral and communication guidelines, including the documentation of patient encounters and methods for sharing patient information with collaborating medical providers.

Also included in the scope-of-practice document should be references to activities that will review the quality of care provided and the methods by which the pharmacist will maintain continuing professional competency for functions encompassed by the scope-of-practice document. A process should be in place, and responsible parties identified, to review and update the scope-of-practice document as appropriate.

Documentation of Services

As members of the interdisciplinary health care team, pharmacists should have access to patients’ health records and authority to make entries necessary for the team’s coordinated care of the patient. With access to the patient’s health record comes the pharmacist’s professional responsibility to safeguard the patient’s rights to privacy and confidentiality. Patients should be informed that pharmacists, as well as other members of the team, have access to their records.

Pharmacists should routinely sign patient-review records at interdisciplinary team meetings. Pharmacist documentation

in patient records should include drug therapy recommendations, monitoring of medication effects, patient and family education and counseling activities, and other activities as indicated. Medication profiles should be maintained and should include information about prescription and nonprescription drug products, dietary supplements, and alternative and complementary therapies. Pharmacists also should maintain detailed formulation files for all extemporaneously compounded dosage forms. Other records should be maintained in compliance with applicable federal and state laws and regulations.

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Suggested Readings

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