



Cancer Connections Online Monthly Forum **2007 Archive Presentation**

The Who, What, and Where of Hospice by Steve Janes, RN, Bozeman Deaconess Hospice

It is always wonderful to hear stories about a new life being brought into this world and yet, as a society, we are fearful of talking about dying. The fact remains that if we are born, we will die, and there are no guarantees about what will happen in between. Death happens to the poor and the rich, the sad and the happy, the young and the old, and nobody can escape this. But what about preparation? We spend our lives preparing for schooling, jobs and careers, families, finances, vacations, retirement, and yet we are rarely prepared for the dying experience.

The concept of hospice is fast becoming a reality in today's health care system. Hospice has as its most basic premise the desire to enhance the quality of one's life no matter the duration of that life. In other words, despite the association of hospice with terminal illness, the primary goal is to help people spend their time living as fully and completely as they wish, in their own, familiar, comfortable surroundings, and in the company of family and friends.

What is hospice?

Considered to be the model for quality, compassionate care for people facing a life-limiting illness, hospice and palliative care involve a team-oriented approach to expert medical care management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well.

Who comprises the hospice team?

The Interdisciplinary Hospice team helps to formulate a plan of care with the goal being to meet the individual needs of the patient and family. Services provided and arranged for by hospice include the following professionals:

PRIMARY PHYSICIAN

- Continues to be involved in the plan of care for the patient.
- Approves any changes in medications, procedures, tests, etc.
- Works with the Hospice team to address comfort measures for the patient.
- Consults as needed with the Hospice Medical Director to achieve good symptom management and quality of life issues.

NURSE

- Introduced at the beginning of Hospice Care.
- Assesses comfort and any other symptoms which may need attentions, such as pain, nausea, etc.
- Performs procedures such as placing and maintaining any IV medications, catheters, wound care, bowel care, blood draws, etc.
- Teaches the caregivers about medications, symptom management, dressing changes, etc.
- Suggests and helps obtain needed equipment and services.
- Offers support and suggestions as physical changes occur.

SOCIAL WORKER

- Works closely with patients and families to create and maintain a supportive home care system.
- Helps address personal, financial and emotional issues.
- Identifies community resources.
- Helps family to arrange added care giving support at home or in alternative care settings.
- Provides information concerning advance directives (living will, comfort one, durable power of attorney).
- Assists in funeral planning and arrangements.
- Suggests coping techniques through relaxation, guided imagery.

VOLUNTEERS

- Team with Hospice Staff to provide a valuable component to the hospice services. Volunteers are extensively trained and carefully screened.
- Provide respite to families/caregivers while patient is sleeping or family needs to catch up on some sleep or needs to leave the house for appointments, errands, shopping, and time with friends and family.
- Read and actively listen to patients.
- Run errands, grocery shopping, laundry, light housekeeping, prepare meals, walk pets, etc.
- Offer outings and companionship for patients.
- Transport to medical appointments.
- Assist with writing memoirs and capturing your life story.
- Socialize with patients in nursing homes and assisted living facilities.

HOME HEALTH AIDE

- Provides personal care needs such as bathing, changing linens, shampooing, shaving, etc.
- Offers light homemaking services.
- Assists in toileting and patient transfers.
- Watches for skin care issues.

- Teaches personal care techniques to families and/or caregivers.

SPIRITUAL CARE COORDINATOR

- Meets with patients and families to share hopes, fears, dreams and concerns, whether spiritual or otherwise.
- Explores unresolved issues surrounding the meaning and value of life.
- Helps with spiritual concerns using a non-denominational approach.
- Supports exploration or struggles with spiritual and/or emotional issues
- Provides spiritual counseling, respecting your personal beliefs.
- Assists in funeral planning, memorial services, or other observances.
- Contacts clergy services from the denomination of your choice.

THERAPY SERVICES

- Evaluate specialized medical equipment.
- Assess transfer safety, strength, and ambulation to improve quality of life.
- Teach safe swallowing/eating techniques.
- Evaluate communication difficulties.
- Teach family/caregivers exercises and positioning for the bed bound patient that might relieve pain and discomfort.

PHARMACIST

- Participates at the team meetings as a medication resource.
- Recommends medication usage and dosage, alternative medications, and optimal medications for symptom management.

BEREAVEMENT

- Offers grief support to families and caregivers through the first year of bereavement. This may include visits, telephone calls, informational packets, and short term counseling.
- Encourages use of the Hospice library for readings on grief work.
- Conducts grief group for Hospice families and also to those in the community experiencing the loss of a loved one.
- Refers to other community resources as needed for grief support.

MUSIC & MASSAGE THERAPY

- Provides a therapeutic relationship between the professional therapist and the patient by facilitating each session following a specialized plan.
- Helps with pain control and anxiety.
- Provides relaxation and emotional expression.

Frequently asked questions about Hospice:

1. When should a decision about entering a hospice program be made and who should make it?

At any time during a life-limiting illness, it's appropriate to discuss all of a patient's care options, including hospice. By law the decision belongs to the patient. Understandably, most people are uncomfortable with the idea of stopping aggressive efforts to beat the disease. Hospice staff members are highly sensitive to these concerns and always available to discuss them with the patient and family.

2. Should I wait for our physician to raise the possibility of hospice, or should I raise it first?

The patient and family should feel free to discuss hospice care at any time with their physician, other health care professionals, clergy or friends.

3. Can a hospice patient who shows signs of recovery be returned to regular medical treatment?

Certainly. If the patient's condition improves and the disease seems to be in remission, patients can be discharged from hospice and return to aggressive therapy or go on about their daily life. If the discharged patient should later need to return to hospice care, Medicare and most private insurance will allow additional coverage for this purpose.

4. Is there any special equipment or changes I have to make in my home before hospice care begins?

Your hospice provider will assess your needs, recommend any equipment, and help make arrangements to obtain any necessary equipment. Often the need for equipment is minimal at first and increases as the disease progresses. In general, hospice will assist in any way it can to make home care as convenient, clean and safe as possible.

5. How difficult is caring for a dying loved one at home?

It's never easy and sometimes can be quite hard. At the end of a long, progressive illness, nights especially can be very long, lonely and scary. So, hospices have staff available around the clock to consult by phone with the family and make night visits if appropriate. To repeat: Hospice can also provide trained volunteers to provide respite care, to give family members a break and/or provide companionship to the patient.

6. Does hospice do anything to make death come sooner?

Hospice neither hastens nor postpones dying. Just as doctors and midwives lend support and expertise during the time of child birth, hospice provides its presence and specialized knowledge during the dying process.

7. Is caring for the patient at home the only place hospice care can be delivered?

No. Hospice patients receive care in their personal residences, nursing homes, hospital hospice units and inpatient hospice centers.

8. How does hospice manage pain?

Hospice believes that emotional and spiritual pain are just as real and in need of attention as physical pain, so it can address each. Hospice nurses and doctors are up to date on the latest medications and devices for pain and symptom relief. In addition, physical and occupational therapists can assist patients to be as mobile and self sufficient as they wish, and they are often joined by specialists schooled in music therapy, art therapy, massage and diet counseling. Finally, various counselors, including clergy, are available to assist family members as well as patients.

9. Will medications prevent the patient from being able to talk or know what's happening?

Usually not. It is the goal of hospice to have the patient as pain free and alert as possible. By constantly consulting with the patient, hospices have been very successful in reaching this goal.

10. Is hospice affiliated with any religious organization?

No. While some churches and religious groups have started hospices (sometimes in connection with their hospitals), these hospices serve a broad community and do not require patients to adhere to any particular set of beliefs.

11. Is hospice care covered by insurance?

Hospice coverage is widely available. It is provided by Medicare nationwide, by Medicaid in 41 states, and by most private insurance providers. To be sure of coverage, families should, of course, check with their employer or health insurance provider.

12. If the patient is not covered by Medicare or any other health insurance, will hospice still provide care?

The first thing hospice will do is assist families in finding out whether the patient is eligible for any coverage they may not be aware of. Barring this, most hospices will provide for anyone who cannot pay using money raised from the community or from memorial or foundation gifts.

13. Does hospice provide any help to the family after the patient dies?

Hospice provides continuing contact and support for caregivers for at least a year following the death of a loved one. Most hospices also sponsor bereavement groups and support for anyone in the community who has experienced a death of a family member, a friend, or similar losses.

14. Is hospice available after hours?

Hospice care is available on call after the administrative office has closed, seven days a week, 24 hours a day. Most hospices have nurses available to respond to a call for help within minutes, if necessary. Some hospice programs have chaplains and social workers on call as well.

The Role of Opioids in Treating Dyspnea (from "Evidence Matters" excelleRx newsletter April 2007)

What is dyspnea?

Dyspnea is the subjective sensation of being unable to breathe and is experienced by more than 70% of patients who receive palliative care. Dyspnea results when there is a mismatch between the perceived need to breathe and the perceived ability to breathe. Dyspnea can be acute or chronic in nature and is often present with other symptoms such as fatigue, cough, anxiety, and pain. Underlying conditions that may be contributing to dyspnea need to be evaluated and addressed before instituting interventions aimed only at palliating the symptom. Primary causes of dyspnea include chronic disease (heart failure, COPD, neuromuscular disease, etc.); acute, superimposed illness (pneumonia, pulmonary embolism, etc.); and cancer-induced complications (tumor growth, bronchial obstruction, pleural effusions). Other causes are anemia, ascites, anxiety, and depression.

Dyspnea is generally associated with three physiologic abnormalities:

1. Increased respiratory effort needed to overcome a certain load or resistance (e.g., restrictive or obstructive lung disease, or pleural effusion);
2. Increased proportion of respiratory muscle required to maintain a normal workload (e.g., neuromuscular weakness, cancer cachexia);
3. Increased ventilatory requirements (e.g., hypoxemia, hyperapnea, metabolic acidosis, anemia).

Dyspnea may result from a combination of the three previously listed abnormalities. Because so many factors can contribute to the experience of dyspnea, accurate clinical interpretation of any patient's dyspneic experience is very challenging.

What pharmacologic treatments should be used for hospice patients who report dyspnea?

There are a variety of pharmacologic approaches to treating dyspnea, including (but not limited to) bronchodilators, corticosteroids, and benzodiazepines. A systematic review of the use of oral and parenteral opioids showed substantial benefit in reducing the feeling of breathlessness in patients with advanced disease of any cause. For patients with advanced disease and for patients without a chronic respiratory disorder present (e.g. COPD), opioids should be considered first-line therapy as they have been proven to be safe and effective for the treatment of dyspnea.

How do opioids relieve dyspnea?

The exact mechanism by which opioids alleviate dyspnea is unknown. One theory is that opioids decrease respiratory distress both by altering the perception of breathlessness and by decreasing ventilatory response to decreasing oxygen and rising CO₂ levels. Contrary to popular belief, opioids do not improve dyspnea through inhibition of the respiratory drive; rather, opioids improve dyspnea without causing significant deterioration in respiratory function. Another theory of how opioids work in the management of dyspnea is that they affect receptors located in the lungs when administered via nebulization, resulting in peripheral activity without significant systemic absorption. However, some studies suggest that these receptors have little effect on the sensation of breathlessness and results of trials with nebulized opioids have had limited success.

What opioid should I use and at what dose?

While the efficacy of opioids in managing dyspnea has been demonstrated in clinical studies, the optimal dosing and route of administration is highly debated. Most clinicians agree that the best treatment is to initiate therapy with a low dose and increase the dose slowly as needed, since respiratory drive suppression can occur if serum opioid levels rise too quickly. Morphine is the opioid most studied in the treatment of dyspnea; other opioids, such as hydromorphone or codeine, are also effective. The usual dose of morphine in the opioid naive patient is 5 mg orally (preferred route) every four hours, which can be titrated upwards in 25-50% increments until symptoms are controlled. For patients already receiving opioid therapy, the current regimen can be increased by 25-50% depending upon the severity of the dyspnea. Patients requiring at least 30 mg of oral morphine (or equivalent) daily might benefit from a long-acting opioid preparation administered every 12 hours. For these patients, a dose of approximately 10% of the total daily long-acting opioid dose should be made available for breakthrough dyspnea. Nebulized morphine has been used to relieve dyspnea with some success, but, at this time, evidence to support its use is weak. Nebulized morphine should not be used in place of oral or parenteral dosing. Other opioids, such as fentanyl and hydromorphone, have also been used to control dyspnea. One study demonstrated that nebulized fentanyl improved patient perception of breathing, respiratory rate, and oxygen saturation without adverse effects. However, the number of patients in the study was small.

Should I try an anxiolytic agent first?

Anxiolytic agents such as lorazepam are often used to treat dyspnea. While they are effective in relieving the anxiety that may contribute to shortness of breath, they work best in hospice patients who complain of anxiety associated with breathing. Therefore, they should be used as second-line therapy or in combination with opioids because they do not treat the dyspnea directly. To date, there is no evidence to support the routine use of anxiolytics as first-line therapy in patients experiencing dyspnea.

Do opioids hasten death?

Unfortunately, many prescribers are reluctant to use morphine or other opioids to manage dyspnea due to concerns that respiratory depression can hasten death. Studies show that the risk of respiratory depression secondary to opioid use in terminally ill patients is very minimal when therapy is initiated at a low dose and titrated thereafter based on patient response and tolerability. A recent study of hospice patients demonstrated that opioid use causes an extremely small risk of hastened death in the population. Ethically, there is no justification for withholding opioid treatment out of fear of potential respiratory depression.

Conclusion:

1. Dyspnea is a common and distressing symptom in hospice patients.
2. Opioids should be considered as first-line therapy.
3. Start low and go slow when initiating opioid therapy.
4. Nebulized opioids may be effective for some patients, but evidence supporting their use is lacking.
5. Appropriately dosed opioids should not be withheld from patients because of respiratory depression fears.

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