



Comfort

Symptoms Other Than Pain

Learning Activities

Activity 1:

Ask students to read the Gypsy case. Ask them individually or in small groups to identify and focus on three phases of her illness: diagnosis and breaking the bad news; palliative cancer treatment phase; and the last days of her life. For each phase ask them to be prepared to discuss the discussion topics listed at the end of the case with the entire class.

Gypsy

For more than a week before Gypsy escaped from her experiences with lung cancer she had been saying, "I don't understand. How can I be dying? I feel so good." Gypsy had no pain. She was alert, cheerful, and participating in all decisions about her care. Her story helps health professionals know that excellent symptom management is possible today.

When the science and art of palliative care are put into action, a person who faces death from a terminal illness need not suffer agony. Likewise, the person can be awake and able to talk with family and friends until close to the end of life. It is possible for a dying person to feel good and Gypsy's story describes how.

It had been seven and one-half months since Gypsy, a 73-year-old Caucasian woman, had hemoptysis as she sat at the bedside of her dying husband. His decline had been gradual, first peripheral vascular disease leading to multiple surgeries and finally resulting in chronic renal failure treated by dialysis. Yet, Gypsy said she knew at that moment that she had lung cancer. After all, she had smoked 1 to 2 packs of cigarettes per day for 50 years, and her father died from lung cancer at age 42. She always knew she would get lung cancer. Still it wasn't easy when she heard the chest x-ray results at the same time her husband was so near to death. It was difficult for her to undergo diagnostic staging scans only four days after he died and biopsy bronchoscopy two days before Christmas, two weeks after her first hemoptysis.

She learned the test results from her pulmonologist. He was gentle and kind as he told her she had poorly differentiated nonsmall cell lung cancer metastatic to the other lung, both kidneys, and possibly the cervical spine. Surgery, chemotherapy, or radiation therapy couldn't cure her cancer. He promised he would control her symptoms and keep her comfortable. He also suggested that she consult a

medical oncologist and consider chemotherapy or radiation therapy as a means to control the hemoptysis.

The medical oncologist met with Gypsy and two members of her family. He sat down next to Gypsy and talked with her about her lung cancer. As he talked, he drew pictures to show her what he was saying. He showed her where the tumors were in both lungs, both kidneys and her spine. He told her there were therapies that could be used to control her cancer but that none of them could cure her cancer. He talked about the advantages and disadvantages of each therapy and of not doing anything to treat her cancer but doing everything possible to keep her comfortable. Then he asked her which option she preferred.

Gypsy didn't hesitate, she told him that, as a 73-year-old woman, she didn't want to go through chemotherapy; she didn't want to lose her hair. She wanted to try radiation because it was likely to help the hemoptysis, which by now was very disturbing to her. She didn't want to cough and bleed to death.

Gypsy started radiation therapy to her lung. She also saw her lawyer to deal with her husband's estate, revise her own will and to specify her wishes in a living will. She created and signed a durable power of attorney and a durable power of attorney for health care in which she specified no home hospice; she did not want her son and daughter-in-law to take care of her as they had done for her husband. Although his death was peaceful and her son and daughter-in-law valued the caregiving experience, Gypsy did not want them providing the level of personal, intimate care to her that they had willingly provided to her husband; she could accept that care from strangers, but not family.

Medical and nursing management of Gypsy's pain and other symptoms were guided by the guidelines proposed by the World Health Organization, the Analgesic Ladder. A summary of how the Analgesic Ladder was implemented serves as an exemplar to health care providers in producing the outcome of total pain relief as a person dies from cancer.

In addition to the hemoptysis at diagnosis, Gypsy reported pain at a level of 4 on a 0 to 10 scale, where 0 was no pain and 10 was pain as bad as it could be. This pain was reported as located in her shoulder and arm, but when she used a body outline to show where her pain was located, the etiology of her pain was clear to her pulmonologist. Her drawing reflected pain in her right scapula that radiated down her arm in the distribution of the C5-6 dermatomes. A bone scan was suggestive, but not conclusive for metastatic disease in the C5 vertebral body.

Consistent with the Analgesic Ladder, her palliative radiation port included the cervical spine for pain control and lung tumor sites for hemoptysis control. Primary pain control advocated in the WHO guidelines is antitumor therapy. Because pain control from antitumor therapy can be delayed for weeks, it is crucial that analgesic therapy be used concurrently. In accordance with the first

step of the Analgesic Ladder, a nonsteroidal anti-inflammatory agent, Naprosyn 375 mg BID was used in addition to antitumor therapy. Because her pain location indicated neural involvement in addition to somatic (bone) involvement, she also received a prescription for amitriptyline 50 mg at bedtime. She began the amitriptyline at 25 mg to minimize anticholinergic effects and escalated the dose to 50 mg after 4 days. Additionally, a mild anxiolytic was prescribed for her normal human response to a new diagnosis of a terminal illness. Atarax 50 mg every 4 to 6 hours as needed effectively controlled her anxiety. She used three doses total in the first week of her radiation therapy. Additional anxiolytics were not needed until the last hours of her life, in part, because of care provided by a cancer pain clinical nurse specialist (CNS). The CNS worked with Gypsy to help her to understand her condition, discuss her needs with her physician, and make decisions about her care as a partner with her physician and family. Maintaining control was important to Gypsy and she achieved this goal.

Gypsy's shoulder and arm pain resolved about two weeks after she completed 18 of the prescribed radiation treatments. She developed severe dysphagia. Her radiation oncologist prescribed a swish and swallow solution of Mylanta, Xylocaine, and Benadryl to relieve her dysphagia. Gypsy decided to forego the last two radiation treatments, which prevented further tissue trauma, and carefully selected foods and fluids in order to ease the pain of eating. The acute pain caused by the antitumor therapy resolved after three weeks, but Gypsy did not remain pain-free.

Gypsy required Step II analgesics, opioids for mild to moderate pain, when she developed pain rated as 6 to 8 in her right thigh when she ambulated or stood and as 0 when she sat or reclined. Drawings on the body outline indicated localized pain in the mid lateral right thigh area. She described the pain as a dull ache that increased at night. A bone scan did not reveal metastatic disease and diagnostic procedures ruled out other etiologies of the pain. She received a prescription for Percocet 1 tablet every 4 to 6 hours as needed in addition to continuing the Step I drugs she had been using. She used the Percocet on a scheduled basis during the day and if she awoke at night.

She noted vision changes in the left eye, which proved to be caused by a metastatic lesion to the macula. A brain scan was negative for additional lesions, but dexamethasone 16 mg per day and tapered down to and maintained at 2 mg BID improved her mental clarity. The primary treatment for the macula lesion was 20 radiation treatments. Gypsy inquired about the possibility of radiation treatment to her thigh, but it was denied since the bone scan was negative. She escalated her Percocet dose to the maximum (12 tablets or 4000 mg acetaminophen) with insufficient pain relief.

Gypsy needed Step III drugs. Her pulmonologist prescribed MS Contin 30 mg BID in addition to Naprosyn, Decadron, and increased the Elavil to 75 mg at bedtime. Because of the pain, Gypsy's functional status declined to the point of

using a walker to ambulate in her house and a wheelchair for activity outside. Three months after her thigh pain started, another bone scan finally revealed metastatic disease in the right femur and T12 to L4 vertebrae to which 10 radiation treatments were administered. About two weeks after the radiation, Gypsy was nearly pain free on ambulation and weight bearing. If the radiation had been administered earlier, it is possible that she would have had this level of comfort for several additional months; and would have had the time and energy necessary to make the list and history of her silver serving pieces.

Within a couple of weeks, Gypsy's condition deteriorated. She developed severe pedal edema with skin lesions and urinary urgency. Oral Lasix did not relieve Gypsy's edema and she was admitted to the hospital for IV Lasix. Upon admission, she told her admitting nurse that she wanted to be a no code. She also told her physician to write in her chart that she was a no code. Both the nurse and physician were amazed at her direct approach to the issue.

Given Gypsy's urinary urgency and in preparation for IV Lasix, Gypsy was given the option of a Foley catheter. She readily agreed and was amazed at the amount of comfort it provided her. She had not realized how much distress the urinary urgency had caused her until the Foley relieved it.

After three days of IV Lasix, Gypsy's edema was not improved and progressed to stasis ulcers on both legs in just three days. Since she had told her physician of her wish for no home hospice, he offered her admission to an inpatient hospice unit where her skin breakdown could be treated and her comfort maintained. She agreed to inpatient hospice care.

A few days later, Gypsy began to have hematuria and a week later her red blood cell count was very low. When asked if she would like a blood transfusion, she replied, "Well, that would be just like CPR wouldn't it? I said I didn't want that done. So I guess I don't want any blood transfusions either."

Until 8 hours before her death, her pain was relieved with MS Contin 30 mg BID, Naprosyn 375 mg BID, Decadron 4 mg BID, and Elavil 75 mg at bed time. It was during this time that she stated, "How can I be dying? I feel so good." This outcome was possible because she received excellent hospice care and analgesics following a systematic, rational approach suggested by the WHO Analgesic Ladder. Agents that exerted action at different receptors via different mechanisms in the peripheral and central nervous system were used along with patient education to enhance her adherence with the therapy plan. She received preparatory information to allow her to know what to expect as her disease progressed. Although she had sufficient quantities of opioids available, she never made a suicide attempt nor did she ask her physician to end her life. Instead, she had total pain relief and did not die in agony as she had expected. This level of comfort was possible because a multidisciplinary team had integrated patient education, antitumor therapies, pharmacological management, and expert hospice

care in ways that maximized Gypsy's sense of control and allowed her to have total relief of pain and other symptoms.

In the last 8 hours of her life when she was unable to swallow, intravenous opioids and anxiolytic agents produced sufficient comfort for her family to perceive that she died in peace. They recognized that cancer pain relief is possible. They had observed it in action. People with cancer, family members, and health care professionals are encouraged to learn from Gypsy's true story and to know that cancer pain can be relieved, often through use of a simple treatment plan applied in a systemic manner.

Discussion Topics:

- Describe three indicators of effective end-of-life care for each phase of Gypsy's illness:
 - diagnosis and breaking the bad news;
 - palliative cancer treatment phase; and
 - the last days of her life.
- Describe one indicator of less than effective end-of-life care for each phase of Gypsy's illness:
 - diagnosis and breaking the bad news;
 - palliative cancer treatment phase; and
 - the last days of her life.
- What symptoms did Gypsy experience at each phase of her illness?
 - diagnosis and breaking the bad news;
 - palliative cancer treatment phase; and
 - the last days of her life.
- What symptom that is typical of lung cancer did Gypsy not experience? Why do you think she did not experience this symptom?
- Why do you think Gypsy did not attempt suicide or ask for assisted suicide?
- Describe what you think Gypsy meant when she said, "I don't understand. How can I be dying? I feel so good." Describe your response if you had been her nurse.

Activity 2:

Ask students to read the Gypsy case presented in activity 1 but to focus on the needs of the family. Ask them individually or in small groups to identify and focus on three phases of her illness: diagnosis and breaking the bad news; palliative cancer treatment phase; and the last days of her life. For each phase ask them to be prepared to discuss the following discussion topics with the entire class.

Family-Focused Discussion Topics:

- What types of anticipatory guidance would have been helpful for the family at each phase of Gypsy's illness?
- How might have the medical decisions regarding symptom management affected the family's bereavement?

