***Ethical Issues in Palliative Care***
Series Editors: Muriel Gillick, MD, and Gregg K. VandeKieft, MD, MA

# Do Surrogates Have a Right to Refuse Pain Medications for Incompetent Patients?

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***Abstract***
*The relief of pain is widely considered to be a basic human right. Physicians are expected to make every attempt to relieve pain and suffering, especially in patients who do not have capacity. This article presents a case in which the family of a woman with severe somatic pain from metastatic breast cancer requests that pain medications be reduced and, at times, held. The ethical issues associated with surrogate decision making and the refusal of medical treatments are reviewed. The obligation to treat pain remains paramount despite family objections.* J Pain Symptom Manage 2012;43:299–305. © *2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

***Key Words***
*Right to pain relief, surrogate decision making, refusing treatments*

## *Introduction*

The evaluation and treatment of severe pain remains an ongoing problem despite educational efforts and quality improvement measures.[1–3] Physician factors, patient and family concerns, and institutional and regulatory constraints have all been cited as barriers to cancer pain management.[4–6] The elderly and patients without capacity are particularly vulnerable and at high risk of having their pain undertreated.[7] Pain and palliative care clinicians often need to educate patients and family members who may be reluctant to use strong opioids for moderate or severe pain, as often occurs with advanced cancer or HIV.

Studies have shown that family caregivers share many of the same attitudinal biases against analgesic use as patients,[8–10] yet little guidance is available for clinicians when surrogates or family members attempt to refuse adequate analgesia for patients without capacity. This case reviews the ethical issues associated with a family's refusal of opioids for an elderly woman with severe cancer-related pain.

## *Case*

Ms. P was a 65 year-old female originally from India who had been living and working as a nurse in the U.S. Over the previous year, she had developed a fungating breast mass and chest wall lesions, for which she had not sought medical care. She presented to the hospital with shortness of breath and a near-syncopal episode at her home. Ms. P was found to have a large left pleural effusion and a small right pleural effusion. A chest tube was placed, and she was started on bilevel positive airway pressure

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(BiPAP) in the setting of $CO_2$ toxicity and severe dyspnea. She had made it clear when she had capacity, on initial presentation in the emergency department (ED), that she would not want to be intubated should she have worsening respiratory failure. In addition to her shortness of breath, Ms. P complained of severe pain, 8/10 on a verbal rating scale, in her right chest wall. No specific back pain or radicular symptoms were noted. Pain worsened with lying on her right side and with dressing changes. She had had some relief of her chest wall pain with low dose hydromorphone in the ED, without significant sedation. On transfer to the Medical Intensive Care Unit (MICU), her pain was treated with morphine by intravenous (IV) patient-controlled analgesia. She required approximately 34 mg of morphine in 20 hours, with no significant improvement in analgesia but worsening $CO_2$ retention and sedation. Opioid rotation to a hydromorphone infusion resulted in improved analgesia, with mild-to-moderate sedation. Her arterial blood gases consistently showed high $PCO_2$ while on the hydromorphone infusion. Adjustments to her BiPAP settings were attempted to mitigate hypercarbia, with only moderate success. She also began to show signs of delirium, with waxing and waning mental status, periods of agitation, poor attention, and disordered thinking. A skin biopsy of one of the chest wall lesions revealed metastatic adenocarcinoma of breast origin.

After multiple meetings with family members to discuss the goals of care, in which the patient was too lethargic and sedated to participate, the palliative care team, the family, and the oncology team agreed to offer a chemotherapeutic agent with low toxicity and focus on the patient's comfort. The family realized that her situation was very dire and the likelihood of response to chemotherapy would be "a long shot" given her disease progression. Both the MICU team and the palliative care team believed that the patient was entering the dying phase, which also was communicated to the family.

Throughout Ms. P's hospital course, both in the MICU and on the oncology ward, her family asked the physicians to reduce the infusion rate of hydromorphone and at times to hold it altogether, to allow for wakefulness. This was done on one occasion when Ms. P's siblings visited from out of state but led to such a severe exacerbation of pain that multiple IV boluses of hydromorphone were needed and the infusion was subsequently restarted within a few hours. The family also asked that the patient not receive any neuroleptic or sedative for treatment of her delirium.

Multiple conversations with the family all led to an appreciation that the family wanted to reduce Ms. P's pain medications and hold neuroleptics to observe if her mental status improved, which they would interpret as a sign that the chemotherapy was working. Furthermore, the family sometimes disagreed with the medical team as to how much pain Ms. P truly experienced. The nursing staff observed nonverbal indications of pain on multiple occasions, necessitating additional opioid bolus doses in addition to the standing hydromorphone infusion for comfort.

## *Ethical Analysis*

### *Refusing Undesired Treatments*

It has been well established, both ethically and legally, that patients have the right to refuse any and all medical and surgical treatments even if this results in hastened death.[11] Surrogates, by extension, have the same right to refuse treatments on behalf of patients who lack capacity to participate in medical decision making. The most common reason for withholding or withdrawing treatment is that the intervention is believed to be excessively burdensome by the patient's standards or not consistent with the patient's values and goals. In general, surrogate decision makers, whether family members or designated health care agents, are expected to base their decisions to refuse therapy on the patient's previously expressed preferences (when known), substituted judgment (when possible), or by using a "best interests" standard. In this case, the patient's family members were asking to withhold pain medications as a result of their perception that the pain medications were causing unacceptable sedation, although the elimination of pain and suffering was also a stated goal of care.

### *Avoiding Unacceptable Side Effects*

It is common for physicians, patients, and family members to have concerns about the