“Whatever My Mother Wants”: Barriers to Adequate Pain Management

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Abstract

Opioids are the preferred medications to treat cancer pain; however, several barriers to cancer pain management exist, including those related to the patient, health care provider, and family caregiver. We describe one such situation in which a family member prevents the patient from receiving adequate pain management at the end of life despite interdepartmental and interdisciplinary efforts. This case highlights the importance of understanding and addressing fears regarding opioid use and implementing an integrated approach including oncologists and palliative care physicians, along with early referrals to palliative care.

Introduction

PATIENTS WITH ADVANCED CANCER frequently develop severe and persistent physical and psychosocial symptoms.¹ Pain is the primary symptom affecting 80% to 90% of these patients.² Opioids are the preferred treatment of cancer-related pain.³ Despite increases in the frequency of opioid use, effectively treating cancer pain remains challenging because of health care provider-, patient-, and family caregiver-related barriers.⁴ We are obligated to ensure that patients receive optimal pain control, but only with their consent. There is limited published literature regarding patient-family disagreements regarding opioid use. We present a patient with advanced cancer with severe pain who refused opioid therapy despite multiple attempts by the interdisciplinary palliative care team and the primary oncology team to convince her otherwise. This case also highlights the importance of establishing a relationship with palliative care early in the disease trajectory.⁵

Case Description

Ms. AB was an African American woman in her early forties who was diagnosed with T-cell lymphoblastic leukemia with a mediastinal mass and a right-sided pleural effusion. Prior to the diagnosis, she was healthy, exercised regularly, had no significant medical history, worked as a business executive, and was a single mother to a teenaged child. Her only other close relative was her recently widowed mother, who lived in a nearby city.

Her treatment comprised two regimens of chemotherapy and an autologous stem cell transplant, all resulting in pro-

gressive disease. Her complications included peripheral neuropathy, labial abscess, myelosuppression, neutropenic fevers, septic shock, recurrent pleural effusions, anxiety, dyspnea, and chest pain, and she was admitted to the intensive care unit (ICU) and underwent thoracentesis several times. She was evaluated by the psychiatry team and duloxetine and lorazepam were initiated for her anxiety. Oxycodone, methadone, and later, hydromorphone were used to alleviate her pain. Her mother was always present at her bedside, even during procedures such as thoracentesis and lumbar punctures.

Approximately 1 year after her initial diagnosis, Ms. AB was admitted in the ICU with pericarditis, yeast septicemia, septic shock, atrial fibrillation, and congestive heart failure. She and her mother were told that no further cancer treatment options were available, and hospice was recommended. The distressed mother was confrontational and reluctant to take her daughter home to receive hospice care, which prompted a consultation with the palliative care team.

During the consultation, we noted that the patient had significantly high symptom distress on multiple scores of the Edmonton Symptom Assessment Scale (ESAS)⁶ (Fig. 1).

The patient's Memorial Delirium Assessment Score (MDAS)⁷ was normal (1/30). Because of uncontrolled pain and dyspnea, we started administering a hydromorphone infusion of 0.2 mg per hour and a bolus of 0.6 mg per hour as needed. The palliative care physician and chaplain initiated counseling and end-of-life discussions with the patient in the absence of her mother as the mother refused to participate. Ms. AB was then transferred to a regular medical floor after a 12-day stay in the ICU, where the palliative care child life

FIG. 1. ESAS score upon palliative care consultation in ICU.

specialist also counseled her on communicating her prognosis with her child, who was living with her friend at the time.

She later became drowsy and mildly confused (MDAS 7/30). Total parenteral nutrition was started. At that time, the patient's mother, who was the medical power of attorney, demanded that the hydromorphone infusion be discontinued and that the patient be started on opioids as needed. The mother advised the patient not to use any pain medications as they would interfere with her cognition and function and would prevent her from receiving any further chemotherapy. The palliative care team provided frequent medication education; however, the patient and/or her mother were unresponsive, and administration of hydromorphone was changed to as-needed dosing. For the next 4 weeks the patient had fluctuating mild delirium (MDAS 5–8/30), but during the majority of the time her mental status was normal. She complained of pain (9/10 on ESAS) in the right chest area but refused any pain medication. Frequent attempts made by the interdisciplinary palliative care team to counsel and support the mother were rejected. Ms. AB was then found to have gross hematuria with the passage of large clots due to BK virus-associated hemorrhagic cystitis. The urology service was consulted, and continuous bladder irrigation was initiated. Ms. AB complained of severe pain (10/10) associated with bladder spasms, as evidenced by crying and screaming, yet she continued to refuse pain medication. The palliative care team provided extensive opioid education and counseling to the patient, and she eventually consented to receiving a morphine infusion of 0.5 mg per hour and a nursing bolus of 1 mg every hour as needed. However, her mother was upset with her for consenting to the morphine infusion, which yielded very minimal relief, and the patient thereafter refused boluses to help relieve severe pain associated with bladder spasms.

This refusal greatly distressed the primary team, the nursing staff, and our palliative care team. Ms. AB deferred all decisions to her mother and said, "Whatever my mother wants," in response to suggestions for treatment. The mother insisted on more aggressive care, including treatment for the BK virus, chemotherapy, and another stem cell transplant. Meanwhile, the mother continued to be hostile toward the palliative care team and repeatedly asserted, "I know what's best for my daughter." Attempts to educate the patient regarding an increase in morphine dosage usually ended with

her mother asking the team to leave the room. The patient's mother visited the patient advocate and hospital administrators daily to complain about the medical teams involved in Ms. AB's care. Meanwhile, Ms. AB continued to experience severe pain associated with bladder spasms. Both the primary team and the palliative care team initiated discussions regarding code status, and the patient deferred all decisions to her mother. The mother insisted that she continue to pursue aggressive treatment.

Two physicians completed a do not resuscitate (DNR) order, and an ethics consultation called for the team to initiate adequate pain management, discontinue aggressive care, and focus mainly on comfort measures. Despite an extensive family conference regarding her prognosis and the goals of care, Ms. AB continued to refuse adequate pain medication and declined hospice care. We offered a transfer to our acute palliative care unit, which was declined by her mother. Two days later, as dyspnea worsened, Ms. AB underwent thoracentesis without premedication with opioids at the insistence of her mother. She died shortly afterwards with her mother at her bedside.

Discussion

At her mother's insistence, our patient declined opioid analgesics to control severe pain, despite interdisciplinary efforts by the oncology and palliative care teams to convince her otherwise. She could have also obtained significant relief from dyspnea with optimal opioid use.^{8–10} In the absence of delirium, psychosis, or severe depression, as assessed by both the psychiatry and palliative care teams, Ms. AB was considered to be competent to make these decisions on the basis of the following principles, as previously described by other authors:^{11–13}

- *Ability to understand the relevant information pertaining to the diagnosis and treatment and the associated benefits and risks with and without the treatment.* Our patient had a very clear understanding of the diagnosis of end-stage acute myeloid leukemia, stem cell transplantation, BK virus-associated hemorrhagic cystitis, and pain as a result of the primary mediastinal mass and the passage of clots from the urethra. She was also informed about the benefits and side effects of opioid therapy and the potential benefits of pain control.

- *Ability to understand the situation and its consequences.* Our patient acknowledged her disease process and also had insight into its terminal nature.
- *Ability to weigh the pros and cons of the treatment options and ability to reason why one option is preferred over the other.* Our patient firmly believed that opioids cause significant side effects and debility, thereby reducing her options for further treatment. She acknowledged the potential for improved pain and quality of life with pain medications.
- *Ability to communicate a choice of treatment based on the points above.* Despite our frequent efforts to convince the patient to allow opioid treatment through counseling and opioid education, our patient decided not to pursue aggressive pain management. She clearly communicated that with us on several occasions.

When the benefits of a treatment outweigh the harm, the patient refusing treatment is subjected to testing for a higher threshold of competency, as described above.¹³

A patient can make decisions with autonomy but may be influenced by external factors such as family coercion, as evidenced in this case. Our patient endorsed her mother's recommendations in a state of excellent cognition on multiple occasions. Therefore, the view of our interdisciplinary palliative care team was that the patient was making this decision with complete autonomy. However, had the patient been incompetent, there would have been limits to the rights of the mother to refuse pain medications, as clearly outlined by Blinderman¹⁴ in a recent publication.

A competent person has a right to refuse life-sustaining therapies such as mechanical ventilation, blood products, and medications.^{15,16} However, negotiation has been proposed as a method of dealing with patients who refuse treatment.¹⁷ This technique enables health care providers to reach a compromise with patients without affecting their sense of autonomy. In our case, the patient agreed to a low-dose morphine infusion after major efforts by our team to educate and counsel her. However, the level of pain control was not satisfactory. Although the morphine dosage could have been increased substantially, it was a compromise agreed upon by both the patient and our team. This trust should have been built upon gradually, thereby leading to successful pain management, but that did not happen in this case. Whenever we made some progress with the patient regarding the use of opioids, her mother intervened.

In addition to negotiation, education and counseling regarding the benefits of pain control, appropriate use of opioids, side effects, addiction, and tolerance at the time of initial consultation for pain management and also at subsequent visits¹⁸ could have helped alleviate the fear of opioids expressed by the patient and her mother. But, having been consulted so late in the disease trajectory, when a barrier was already in place between the mother and the health care team, a relationship of trust could not be developed, despite several attempts. This also prevented us from gaining further insight into the mother-daughter relationship and from providing counseling to the mother. This further validates the need for early palliative care referrals.⁵

Both family caregivers and patients can prevent the implementation of effective pain management.⁴ Patients can underreport their pain and refuse pain medication for a va-

riety of reasons,^{19–22} including concerns about opioid addiction and side effects, the desire to please their physician by not complaining, and the assumption that increased pain is related to disease progression. Moreover, patients with uncontrolled pain are more reluctant to report pain and use analgesics than patients whose pain is well controlled.¹⁹ Family caregivers can be potential barriers to effective pain management, especially in patients with poor performance status.²¹ In addition to the reasons outlined above, they also tend to believe that pain distracts the physician from treating the patient's cancer adequately.¹⁹ This certainly was the case with our patient's mother. Patient and family education has been shown to help overcome these barriers.¹⁸ However, despite efforts to educate our patient and her mother about the need for opioids and the adverse consequences of untreated pain, our team was unsuccessful in convincing her that adequate pain management would not hinder her chances for undergoing further treatment. This resulted in a significant amount of distress among our team about our inability to provide the best possible care for the patient. Health care professionals are at a high risk for burnout when they are prevented from performing a morally obligated duty.^{23,24}

All procedures in the medical field come with a certain risk of failure. Similarly, palliative care interventions are sometimes inadequate despite maximum effort by the interdisciplinary team. Many palliative care teams have probably encountered this situation. This case highlights the significance of understanding the unique patient-family issues that can prevent adequate pain control in terminally ill cancer patients. Future studies should focus on understanding barriers to adequate pain management and the role of patient and family education regarding the use of opioids as a tool for overcoming such barriers. Regular debriefing by our palliative care team and realizing that we cannot "fix" everything despite our best possible efforts helped us cope with this moral distress.

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