A Young Adult with Duodenal Neuroendocrine Tumor Transitioning to Home Hospice

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Abstract

Adolescents and young adults diagnosed with a terminal illness benefit greatly from an early introduction to hospice and palliative care. Many young patients do not have these conversations early on in their care, often leading to unmet goals of treatment. In our case, we present a twenty-two-year-old patient with a history of duodenal neuroendocrine tumor that was past the point of curative treatment. Early end-of-life discussions were imperative to his care.

Background

Neuroendocrine tumors (NETs) are rare tumors, although beginning to increase in incidence.[1] Duodenal NETs account for approximately 4% of all gastrointestinal NETs.[1,2] Most duodenal NETs are nonfunctional and incidentally discovered; however, symptomatic cases may present with epigastric pain, bleeding, obstruction, or complications from metastatic disease, leading to high mortality rates.[3,4]

Adolescents and young adults (AYA), defined as individuals aged 15 to 39, have unique developmental and psychosocial needs when diagnosed with life-limiting malignancies. They are at a stage of life where health issues can cause major disruptions to relationships, education, and employment.[5] These challenges are amplified by a comparatively lower coping capacity than most adult patients. When a patient is diagnosed with a terminal prognosis, it is pivotal that palliative and goals of care discussions are not delayed, especially when that patient is in the category of AYA. Although it is challenging, the earlier these productive conversations can be held, the sooner patient preferences can be incorporated into care.6 Our objective is to present a case highlighting the importance of early goals-of-care discussions in young patients with advanced disease and to demonstrate that hospice can be an appropriate and meaningful option regardless of age.

Case Presentation

A 22-year-old male, diagnosed with a duodenal neuroendocrine tumor metastatic to the liver and pancreas, experienced repeat hospitalizations for abdominal pain, intractable nausea and vomiting, recurrent pancreatitis, and portal vein thrombosis. He presented to our facility for continued abdominal pain, nausea/vomiting, along with severe malnutrition and failure to thrive. His prior interventions included placement of a left hepatic internal/external biliary stent and a biliary drain. He had delayed initial chemotherapy treatment after initial evaluation, and at that time, next-generation sequencing revealed Microsatellite Instability (MSI)-high status, high tumor mutational burden, and non-targetable

mutations including SMARCA4 and TP53. After undergoing one round of chemotherapy with carboplatin and etoposide, his symptoms continued to worsen, and he remained hospitalized.

Investigation

Imaging revealed an enlarging duodenal mass causing complete luminal obstruction, marked gastric distention, and progression of hepatic and now pancreatic metastases. The GI team attempted Endoscopic Retrograde Cholangiopancreatography (ERCP) for pancreatic stenting but were unsuccessful due to the anatomical difficulties.

Treatment

The patient required multiple escalating pain regimens and antiemetics to help control his symptoms. Significant relief was ultimately achieved only after gastric decompression via nasogastric tube. He could not tolerate oral intake, so total parenteral nutrition was started, and anticoagulation for portal vein thrombosis was reconsidered due to his poor prognosis. Oncology explained that due to the progression of his tumor, curative or disease-modifying options were no longer feasible. Pain control became increasingly challenging, necessitating hydromorphone (patient-controlled) and ultimately a celiac plexus block, which provided substantial improvement until progressive disease again caused severe back pain requiring transition to a hydromorphone via a continuous ambulatory delivery device (CADD). For comfort, a gastric decompression tube and separate jejunal feeding tube were placed, as a combined gastro-jejunal tube was not possible due to the tumor burden altering his anatomy.

Outcome

Initially, it was difficult to hold goals of care conversations with the patient. When the team would approach him with the subject of hospice and end-of-life care, he would become anxious and ask to delay the discussion. Over time, many conversations were held with the patient, his family, and the full care team, which included palliative care, oncology, and the primary medical team. Together, we held discussions regarding his prognosis and increasing symptom burden and asked about his care goals.

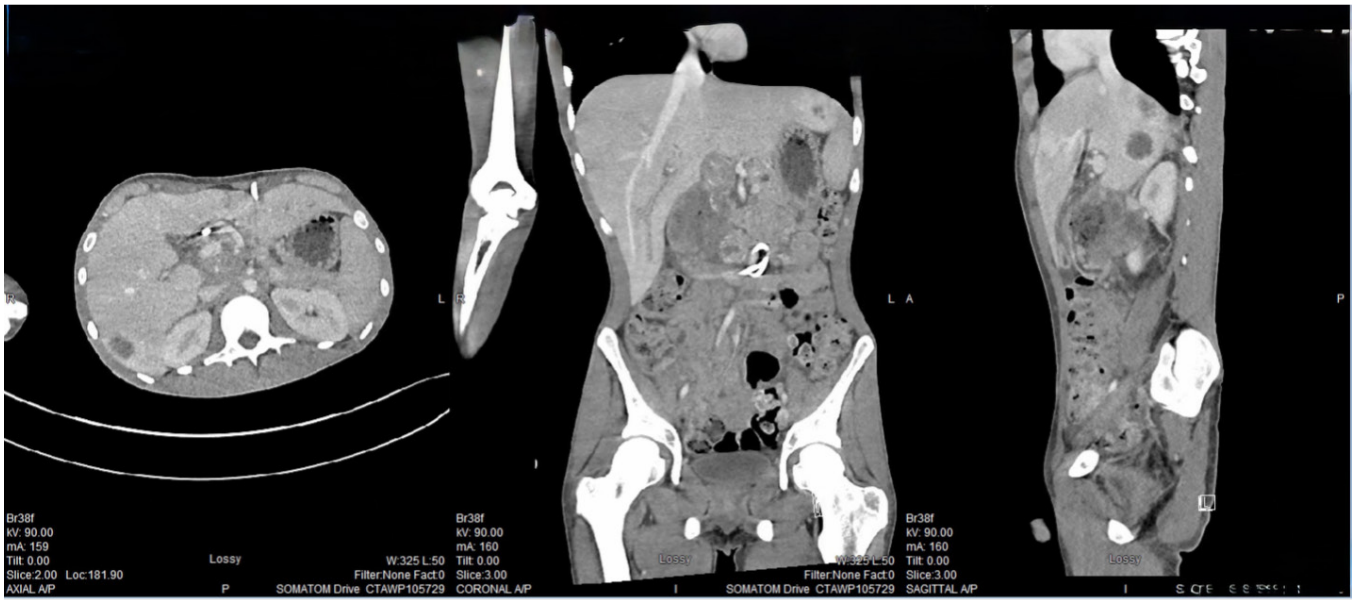

Figure 1. Contrast-enhanced CT of the abdomen demonstrating marked gastric distention secondary to complete luminal obstruction of the duodenum from an advanced neuroendocrine tumor, with progression of hepatic metastases and pancreatic duct dilatation.

He explained that comfort was his main priority and that he wanted to spend the time he had left at home. Using shared decision-making, we determined that transitioning to comfort care with the plan for home hospice best aligned with his values. After his pain was controlled with the celiac plexus block, the CADD pump, and decompression with feeding tubes, he was medically stable for discharge with home hospice.

Discussion

Our patient's case was unique not only because of the rarity of his malignancy, but also because of his age at the time of transition to hospice care. Adolescents and young adults often face additional challenges at the end of life, including psychosocial and emotional factors.[6] In our case, this proved true when trying to speak to our patient about his end-of-life wishes. e would become extremely anxious, nauseous, and postpone these conversations. Many of these challenges stem from provider discomfort and uncertainty regarding prognosis, which can delay hospice and goals-of-care discussions.[6] Early involvement of palliative care is crucial to ensure that treatments align with patient values and desires. Studies show that these discussions often take place very late in the disease course, frequently within the last thirty days of life.[7] In this situation, our patient was in the hospital for weeks before initiating full comfort care, likely reflecting a combination of patient-related distress and delayed initiation of goals-of-care discussions.

Patients with terminal illness and severe symptom burden benefit greatly from palliative care. In young adults with cancer, palliative services can improve symptom control with various methods that emphasize comfort-focused care.[8] In our patient, worsening tumor burden led to severe gastrointestinal obstruction, refractory pancreatitis, and malnutrition. After discussions with him about his goals, it was clear that his priorities centered on comfort and spending time at home. Through ongoing discussions with the patient, his family, and the full care team, we determined that shifting our management of his condition from treatment-directed to comfort-directed care was both clinically and ethically justified.

This case helps highlight the ethical principles that can guide end-of-life care. When further treatment is unlikely to provide benefit or could increase suffering, it is appropriate to limit interventions, while still respecting patient autonomy.[9] Having early goals-of-care discussions with our patient allowed us to align his treatment plan with his values and ultimately gave him more pain-free days near the end of his life. Coordination with all specialists, including oncology, palliative care, and the primary team was essential in supporting the patient, his family, and friends throughout this process.

Conclusion

Although hospice is uncommon in someone so young, this case emphasizes that age alone should not determine what appropriate care looks like. Important considerations when discussing end-of-life care in these situations include patient autonomy, comfort, and ethical considerations. Early palliative involvement and goals-of-care discussions helped us determine what mattered most to this patient, which was comfort and time at home. Hospice was ultimately the most appropriate choice to align his care with his values when it became clear that the disease process was irreversible. Interventions that prioritized pain control and nutritional support were central to maintaining his quality of life. This case demonstrates the importance of proactive palliative care for adolescents and young adults with terminal diseases. Hospice can be a meaningful option regardless of age, and that early conversations with patients can spare them from prolonged pain and discomfort at the end of their lives.

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