Journal of Integrative Nursing and Palliative Care (JINPC)

Case Report

Volume 5 | Page 83-88

Optimizing Pain Management in Palliative Care for a Patient with Intestinal Failure: A Case Report

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Abstract

Pain management in patients with irreversible intestinal failure poses unique challenges, requiring a multidisciplinary strategy that addresses complex pharmacological needs, systemic complications, and prognostic uncertainty. This report describes a patient with gastrointestinal hypoganglionosis whose pain was refractory to conventional opioids due to intestinal malabsorption and dysmotility. Subcutaneous ketamine was successfully employed as an alternative analgesic. Optimal care relied on close interdisciplinary collaboration; however, discrepancies between the patient's hope for curative treatment and the life-limiting nature of her condition delayed advance care planning and smooth transitions to community-based support.

The rarity of the condition and associated prognostic uncertainty underscore the importance of early integration of palliative care for patients with non-malignant intestinal failure. Tailored care models that effectively link hospital and community services are crucial to align treatment goals with patient and family priorities and to prevent fragmented care during critical transitions.

Keywords: Hypoganglionosis, Gastrointestinal, Intestinal failure, Pain management, Palliative care

Introduction

Providing palliative care for individuals with chronic non-cancer illnesses presents challenges distinct from those in cancer-focused care [1, 2]. In particular, pain management in patients with intestinal failure involves complex interactions between pharmacological interventions, physiological complications, and psychosocial factors, often exceeding the scope of conventional palliative strategies [3].

Adult-onset hypoganglionosis is a rare disorder affecting the enteric nervous system, characterized by a decreased density of ganglion cells in the intestinal myenteric and submucosal plexuses, resulting in impaired gastrointestinal motility and chronic abdominal pain [4–6]. Representing approximately 3–5% of intestinal innervation disorders [4–6], it commonly manifests as constipation, recurrent abdominal discomfort, distension, nausea, vomiting, and episodes of intestinal obstruction [5, 7]. Diagnosis is challenging due to the non-specific clinical presentation and typically requires endoscopic evaluation combined with full-thickness intestinal biopsies [4, 7]. Pain arises from multiple mechanisms, including bowel distension, intermittent obstruction, inflammation, and visceral hypersensitivity [4, 6, 7].

This case report examines the complex pain management challenges and prognostic uncertainties in a patient with gastrointestinal hypoganglionosis, alongside a discussion of palliative care strategies for intestinal failure in chronic non-malignant conditions.

Case presentation

Clinical history

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Received: 19 April 2024; **Revised:** 21 September 2024; **Accepted:** 08 September 2024; **Published:** 30 September 2024

How to Cite This Article: Suhail H, Bihari E, Lempel E. Optimizing Pain Management in Palliative Care for a Patient with Intestinal Failure: A Case Report. J Integr Nurs Palliat Care. 2024;5:83-8. https://doi.org/10.51847/W1ty4wyGGW

The patient, a woman in her late 20s, experienced recurrent small bowel obstructions (SBOs) beginning in 2020, resulting in repeated hospitalizations for undifferentiated abdominal pain. Her prior medical and surgical history was unremarkable. In June 2022, after her eighth admission in under two years, she underwent a right hemicolectomy for caecal volvulus. Histopathological analysis revealed hypoganglionosis in the terminal ileum and caecum. Postoperatively, she required total parenteral nutrition (TPN) delivered via a tunneled central venous catheter (CVC) at three liters per day. She was followed closely by her gastroenterologist and multidisciplinary intestinal failure team in the outpatient setting.

In January 2023, she was diagnosed with stage IV endometriosis. Between March and September 2023, she underwent multiple peripherally inserted central catheter (PICC) placements for intravenous hydration, antibiotics, parenteral analgesics, and antiemetics. Analgesic management by the Acute Pain Service (APS) included sublingual buprenorphine (200–400 µg PRN every four hours), oral tramadol (50–100 mg PRN every four hours), transdermal buprenorphine (5–10 µg/hour weekly), fentanyl patches (max 12 µg/hour weekly), and oral tapentadol SR (50 mg twice daily). Despite frequent adjustments, pain control remained inadequate, and oral/topical agents were often ineffective, leading to intermittent noncompliance. Ultimately, brief courses of intravenous ketamine were the only effective analgesic intervention.

From November 2023 to February 2024, she underwent exploratory laparotomy, adhesiolysis, ileocolic resection, and end-ileostomy, complicated by superior mesenteric vein and PICC-associated thromboses. This period saw rapid functional decline; she became wheelchair-dependent, able to walk only 15 meters, and her weight dropped to 32 kg by August 2024, a 45% reduction from her pre-illness baseline.

Palliative care management

The palliative care team was first involved during an August 2024 admission for partial SBO, presenting with colicky abdominal pain distinct from her endometriosis-associated pain. Examination revealed abdominal distension, diffuse tenderness, and reduced bowel sounds. Gastric decompression via nasogastric and ileostomy tubes was performed, and APS was consulted.

Given her impaired gastrointestinal absorption and previous sublingual opioid ineffectiveness, analgesia was limited to parenteral routes. Initial IV tramadol, clonidine, and fentanyl provided insufficient relief. Ketamine infusion was initiated at 2 mg/hour and titrated to 8 mg/hour over two days alongside IV clonidine 25 µg three times daily, without adverse hemodynamic or neuropsychiatric effects.

A PICC line obstruction required conversion to continuous subcutaneous infusion (CSCI) of ketamine (200 mg/24h) and subcutaneous clonidine (25 µg three times daily). As the SBO resolved, ketamine was tapered to 150 mg and then 75 mg/24h, followed by transition to oral ketamine lozenges (25–50 mg PRN every six hours). Secondary analgesia with low-dose subcutaneous hydromorphone (0.2–0.4 mg PRN hourly) was added without background opioid therapy.

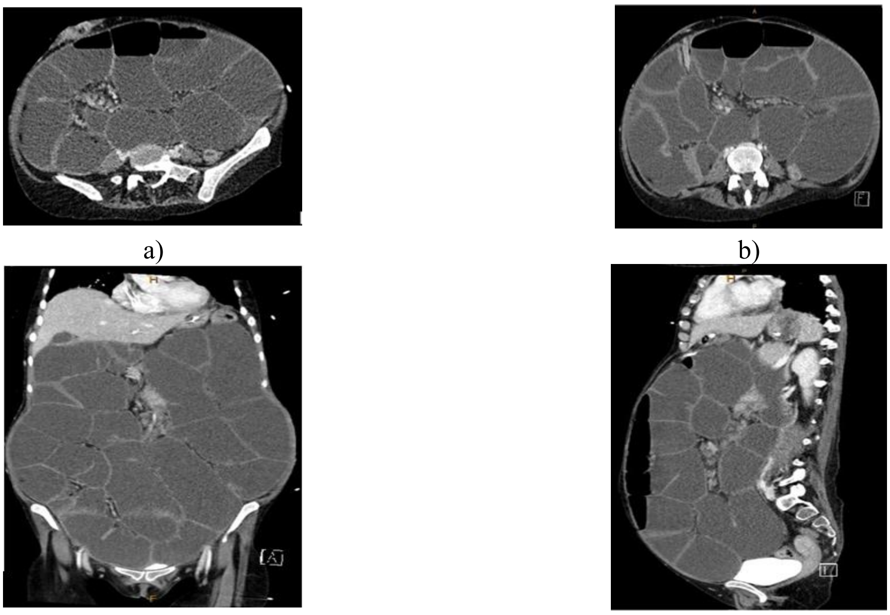
a) b)
c) d)

Figure 1. Abdominal Computed Tomography (CT) showing gastrointestinal ganglionosis with superimposed bowel obstruction in transverse (a and b), coronal (c) and sagittal views (d)

Case challenges and palliative care coordination

Although the initial referral to palliative care indicated a limited prognosis of several months, neither the patient nor her family accepted this outlook. Her mother actively sought second opinions from private gastroenterologists in pursuit of ongoing curative interventions. This divergence complicated discussions regarding prognosis and advance care planning, including limitations on high-intensity treatments such as surgery or intensive care. Despite repeated discussions, the patient and her family maintained that her condition was not life-limiting.

As her clinical status stabilized, the palliative care (PC) team faced obstacles in discharge planning, navigating the constraints of community-based palliative services for a patient unwilling to acknowledge the terminal nature of her illness. Given her desire for active treatment, community teams initially declined to provide home-based medical and nursing support for sublingual ketamine and parenteral hydromorphone. Collaborative efforts involving the Acute Pain Service (APS) and the Chronic Pain Service (CPS) were attempted to establish a community care model; however, prior non-attendance at outpatient CPS appointments led to reluctance to re-engage.

Despite these challenges, the inpatient PC team successfully arranged for community-based support upon discharge. The patient was discharged after a 50-day hospital stay with intravenous cyclizine 50 mg three times daily and daily TPN via her tunneled CVC, without the need for additional background or as-needed analgesia. Shortly after discharge, she developed septic shock due to a tunneled CVC infection and was readmitted within 24 hours. A goals-of-care discussion, led by her gastroenterologist and the hospital intensivist, determined that intensive care interventions would not benefit her quality of life. Her care plan focused on reversible interventions, including CVC removal, which she consented to. While awaiting the procedure, she experienced sudden cardiac arrest and died on the ward, with her family present, within 36 hours of discharge.

Results and Discussion

Pain management challenges in intestinal failure

Intestinal failure (IF) is defined by the inability to sustain adequate nutrition or fluid-electrolyte balance without parenteral support and frequently leads to chronic visceral pain from structural and functional gastrointestinal abnormalities [8, 9]. Contributing factors include intestinal inflammation, bacterial overgrowth, and dysmotility, which generate both nociceptive and neuropathic pain [10, 11]. The need for parenteral nutrition introduces additional complications, such as catheter-related infections and intestinal failure–associated liver disease, further exacerbating discomfort [9].

Opioids remain a mainstay for pain control in IF, but their use is complicated by the risk of hyperalgesia, dependency, and worsening dysmotility [10, 12, 13]. Oral opioids often fail due to impaired intestinal absorption, necessitating alternative routes such as intravenous, sublingual, or transdermal delivery [8, 10]. Adjuvant therapies, including gabapentinoids, may address neuropathic components, but absorption challenges limit their use. In our patient, parenteral clonidine was utilized successfully as an adjunct.

Transdermal analgesics, including buprenorphine and fentanyl patches, provide sustained pain control and are often preferred for chronic visceral pain in IF. Buprenorphine's partial μ-opioid agonist and κ-antagonist profile reduces constipation relative to full opioid agonists [14]. However, adequate dermal perfusion is required, which may be compromised in malnourished or cachectic patients [15]. Sublingual formulations circumvent intestinal absorption issues, offering rapid analgesia during acute pain episodes [14, 15]. Limitations include potential worsening of ileus, bacterial overgrowth, dependency risk, regulatory restrictions, and local skin reactions in up to 30% of patients [10, 14, 15].

Emerging pharmacological options include teduglutide, a GLP-2 analogue that enhances intestinal adaptation and reduces abdominal discomfort [16]; eluxadoline, a peripherally acting μ-opioid agonist/δ-antagonist for visceral hypersensitivity [17]; and low-dose transdermal clonidine, which mitigates colonic hypermotility and pain via α2-adrenergic mechanisms [18]. High cost, limited availability, and potential adverse effects constrain widespread implementation.

Interventional approaches, such as celiac plexus neurolysis and splanchnic nerve blocks, may benefit selected IF patients. Celiac plexus neurolysis targets sympathetic innervation of the upper abdominal viscera and has been shown to reduce pain in chronic pancreatitis or radiation enteritis by 50–70% for several months [19]. Splanchnic nerve blocks are preferred for retroperitoneal fibrosis or extensive adhesions [20]. Long-term neuraxial interventions are generally unsuitable in IF due to heightened risks of autonomic instability, motor blockade, muscle wasting, and catheter-related infections [21].

Non-pharmacological strategies, including cognitive-behavioral therapy and acupuncture, are underutilized despite evidence supporting their role in reducing opioid dependence [22, 23].

Interdisciplinary care coordination and service delivery models

Managing this patient's complex condition required coordinated input from multiple disciplines, including gastroenterology, surgery, acute and chronic pain services, and palliative care. Evidence shows that multidisciplinary collaboration enhances symptom control and overall quality of life. For example, a Chinese study of 92 hospitalized cancer patients found that individualized care provided by a team including surgeons, radiologists, palliative physicians, pain specialists, nutritionists, psychologists, and nursing staff significantly reduced pain levels during concurrent chemotherapy [24]. In Australia, structured chronic pain programs with telephone follow-ups were associated with a 44% reduction in hospital admissions, emphasizing the importance of continuity and coordinated care [25].

Integration between palliative care and pain management specialists is most effective when structured systems and formal communication pathways exist. Surveys indicate that institutions with regular case conferences and defined collaborative protocols refer patients to pain services more frequently and manage more cases jointly compared to less organized settings [26]. Conversely, barriers such as unclear roles, limited interdisciplinary funding, and insufficient time for complex discussions hinder cooperation [27–29]. Successful models often combine hospital-based consultation with community palliative care, reducing ICU admissions and overall hospitalizations by enabling early symptom control and seamless discharge planning [30, 31]. In this case, stronger collaboration across these services might have prevented the patient's brief and fragmented community discharge. Notably, the patient was not linked to rare disease support networks such as "Rare Voices," which can provide guidance and peer support tailored to rare conditions [32].

Palliative care in non-malignant illness

Patients with non-cancer chronic diseases—including COPD, advanced heart failure, and dementia—represent a substantial proportion of palliative care needs but receive comparatively few specialist referrals [33, 34]. Prognostic uncertainty and variable disease courses frequently delay initiation of palliative care, as clinicians are reluctant to formally categorize patients as "palliative" [34, 35]. In this case, the patient and her family struggled to accept the life-limiting nature of gastrointestinal hypoganglionosis, reflecting both its rarity and limited long-term outcome data [5]. While tools such as the "surprise question" or SPICT can help identify patients who may benefit from palliative interventions, their sensitivity in early or atypical presentations is limited [31, 35].

Early palliative care integration alongside disease-directed therapy has demonstrated improved symptom management and fewer hospitalizations. For instance, early palliative involvement in COPD is associated with reductions in admissions and improved management of fatigue, dyspnea, and pain [35, 36]. Advance care planning and early goals-of-care discussions have similarly been shown to decrease ICU admissions in older adults with severe heart failure [37]. The "Bowtie model" offers a framework to integrate palliative principles from the point of diagnosis, promoting earlier acceptance and aligning care with patient-centered priorities regardless of prognosis [38]. Had this approach been applied in our patient's care, it may have facilitated smoother transitions and reduced distress for both her and her family.

Limitations

Several considerations limited the therapeutic approach in this case. Methadone was not trialed due to concerns about adherence and non-attendance at outpatient services, although its pharmacologic properties—including NMDA antagonism and transmucosal absorption—may make it beneficial for patients with intestinal failure requiring long-term opioids [39–41]. Additionally, intravenous ketamine dosing deviated from standard protocols, a conscious decision made to prioritize patient safety given her frailty and comorbidities [42].

Conclusion

This case illustrates the multifaceted challenges of providing palliative care for intestinal failure secondary to hypoganglionosis. Key lessons include the importance of flexible, individualized pain management strategies, the need for early palliative engagement even in rare, non-malignant diseases, and the critical role of interdisciplinary coordination to optimize patient outcomes and continuity of care.

Acknowledgments: None

Conflict of interest: None

Financial support: None

Ethics statement: None

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