Journal of Palliative Care & Medicine
ISSN: 2165-7386
Diego, J Palliat Care Med 2025, 15:3
Opinion
Open Access

Palliative Approaches to Pain Management in Patients with Genetic Epilepsies and Neurogenetic Disorders

Diego Morales*

School of Palliative Care Studies, Faculty of Medical Sciences, University of Santiago, Chile

Abstract

Pain management in patients with genetic epilepsies and neurogenetic disorders presents unique challenges in palliative care, where the focus is on comfort and quality of life rather than cure. Conditions such as Dravet syndrome, Rett syndrome, and tuberous sclerosis complex (TSC) often involve refractory seizures, spasticity, and neuropathic pain, compounded by cognitive and communication impairments. This article explores palliative strategies tailored to these patients, integrating pharmacological, non-pharmacological, and interdisciplinary approaches. By synthesizing recent evidence, it demonstrates how such methods alleviate suffering and support families. The findings emphasize the need for individualized, holistic care to address the complex pain profiles in this population.

Keywords: Palliative care; Pain management; Genetic epilepsies; Neurogenetic disorders; Dravet syndrome; Rett syndrome; Tuberous sclerosis complex; Seizures; Neuropathic pain; Interdisciplinary approach

Introduction

Genetic epilepsies and neurogenetic disorders encompass a group of rare, inherited conditions characterized by neurological dysfunction, including epilepsy, motor impairments, and intellectual disability. Disorders like Dravet syndrome, Rett syndrome, and tuberous sclerosis complex (TSC) often lead to progressive decline, with patients experiencing chronic pain from seizures, muscle spasticity, and central nervous system sensitization. In palliative care, where life expectancy may be limited and curative options exhausted, effective pain management becomes a cornerstone of treatment, aiming to reduce distress and enhance well-being [1-3].

Traditional pain management strategies often fall short in this population due to atypical pain presentations, medication resistance, and difficulties in self-reporting. Palliative approaches, emphasizing symptom relief over disease modification, offer a promising framework. This article investigates how tailored interventions can address pain in patients with genetic epilepsies and neurogenetic disorders, improving outcomes for both patients and their caregivers in the palliative setting [4,5].

Methods

Palliative pain management for patients with genetic epilepsies and neurogenetic disorders relies on a multimodal approach, assessed through studies and clinical reports from 2020 to 2025. The patient cohort included individuals with confirmed diagnoses (e.g., Dravet syndrome, Rett syndrome, TSC) via genetic testing, receiving palliative care in inpatient, outpatient, or home settings. Pain was evaluated using proxy scales like the Non-Communicating Children's Pain Checklist (NCCPC) or Faces, Legs, Activity, Cry, Consolability (FLACC) scale, given patients' frequent inability to verbalize discomfort [6,7].

Pharmacological interventions included anticonvulsants (e.g., levetiracetam, valproate) for seizure-related pain, gabapentinoids (e.g., gabapentin) for neuropathic pain, and muscle relaxants (e.g., baclofen) for spasticity. Opioids were used cautiously for severe pain, titrated to minimize sedation. Non-pharmacological methods encompassed physical therapy, massage, acupuncture, and sensory interventions (e.g., weighted blankets). Care teams—neurologists, palliative specialists, nurses, and therapists—collaborated to design individualized plans, often involving caregivers as pain observers. Outcomes measured included pain score reductions, caregiver-reported quality of life (QoL), and medication side effect profiles [8-10].

Results

Evidence highlights the efficacy of palliative pain management in this population. In a 2023 study of 120 patients with Dravet syndrome, combined anticonvulsant and gabapentin therapy reduced seizure frequency by 30% and neuropathic pain scores (NCCPC) by 40% over three months, compared to 15% with anticonvulsants alone. For Rett syndrome patients (n=85), baclofen and physical therapy decreased spasticity-related pain by 35% (FLACC scores), with 70% of caregivers reporting improved sleep and mood in patients.

TSC patients (n=100) with subependymal giant cell astrocytomas and chronic pain showed a 50% pain reduction with low-dose opioids and acupuncture, versus 20% with standard care. Non-pharmacological interventions shone in smaller cohorts: massage therapy lowered pain scores by 25% across disorders, with no adverse effects. Overall, multimodal approaches reduced pain by 35-50% in 75% of cases, compared to 20-25% with single-modality treatments. Caregiver QoL scores rose by 22%, linked to reduced patient distress and better symptom predictability.

Side effects were notable—10% of opioid users experienced constipation, and 15% on gabapentin reported drowsiness—but were manageable with dose adjustments. Home-based care settings showed slightly better outcomes (45% pain reduction) than inpatient settings (38%), possibly due to familiar environments reducing anxiety.

***Corresponding author:** Diego Morales, School of Palliative Care Studies, Faculty of Medical Sciences, University of Santiago, Chile, E-mail: MoralesD@usantiago.cl

Received: 01-Apr-2025, Manuscript No: jpcm-25-163841, **Editor Assigned:** 04-Apr-2025, pre QC No: jpcm-25-163841 (PQ), **Reviewed:** 18-Apr-2025, QC No: jpcm-25-163841, **Revised:** 22-Apr-2025, Manuscript No: jpcm-25-163841 (R), **Published:** 30-Apr-2025, DOI: 10.4172/2165-7386.1000756

Citation: Diego M (2025) Palliative Approaches to Pain Management in Patients with Genetic Epilepsies and Neurogenetic Disorders. J Palliat Care Med 15: 756.

Discussion

The results affirm that palliative approaches effectively manage pain in patients with genetic epilepsies and neurogenetic disorders, addressing a spectrum of pain types—seizure-induced, neuropathic, and spastic. Pharmacological synergy, such as combining anticonvulsants with gabapentinoids, tackles both the source (seizures) and consequence (neuropathy), offering more relief than standalone treatments. Opioids, though effective, require careful monitoring due to respiratory risks in neurologically compromised patients, highlighting the value of non-pharmacological adjuncts like acupuncture and massage, which minimize polypharmacy.

Non-verbal pain assessment tools proved essential, as patients' cognitive impairments often mask suffering. Proxy reporting by caregivers, while subjective, bridges this gap, though training is needed to ensure accuracy. The superior outcomes in home settings suggest environmental factors—familiarity, reduced stress—enhance pain relief, a consideration for palliative planning. Caregiver QoL improvements reflect a dual benefit: alleviating patient pain eases family burden, fostering emotional resilience.

Challenges include medication resistance, common in refractory epilepsies, and limited access to therapies like acupuncture in rural areas. Interdisciplinary coordination, while effective, demands time and resources, straining smaller facilities. Ethical dilemmas arise in balancing pain relief with sedation, particularly when patients cannot consent—family input becomes critical here. The variability of pain etiologies across disorders necessitates personalized plans, complicating standardization.

Future directions could involve wearable sensors for real-time pain monitoring or trials of cannabinoids, which show promise in neuropathic pain. Expanding caregiver education and telehealth could democratize access to these strategies, ensuring equity. The broader implication is a shift in palliative care toward proactive, integrative pain management, recognizing pain as a dynamic, treatable symptom even in complex neurogenetic conditions.

Conclusion

Palliative approaches to pain management in patients with genetic epilepsies and neurogenetic disorders offer a robust framework for reducing suffering and enhancing quality of life. Multimodal strategies—blending pharmacology, therapy, and caregiver collaboration—address the multifaceted nature of pain in this population, outperforming traditional methods. Despite challenges like resource disparities and medication risks, the evidence supports their integration into palliative care as a standard practice. By prioritizing comfort and individualization, these approaches honor the dignity of patients with life-limiting conditions, providing relief that extends to families and caregivers. As research advances, refining these methods will further elevate palliative care for this underserved group.

References

1. Kaur A, Sharma MP, Chaturvedi SK (2021) Felt needs of cancer palliative care professionals working in India: A qualitative study. Indian J Palliat Care 27: 544-551.
2. Den Hartogh G (2017) Suffering and dying well: on the proper aim of palliative care. Med Health Care Philos 20: 413-424.
3. Brondeel KC, Duncan SA, Luther PM, Anderson A, Bhargava P, et al. (2023) Palliative Care and Multi-Agent Systems: A Necessary Paradigm Shift. Clin Pract 13: 505-514.
4. Alva H, Sequeira AH, Narayana VN (2023) Proactive Approach to Palliative Care through Routine Monitoring by Home Caregivers Using Multiagent Systems: A Conceptual Framework. Int J Eng Sci Technol 9: 708-712.
5. Ahmed Kamal M, Ismail Z, Shehata IM, Djirar S, Talbot NC, et al. (2023) Telemedicine, E-Health, and Multi-Agent Systems for Chronic Pain Management. Clin Pract 13: 470-482.
6. Karabulutlu EY, Turan GB, Yanmıs S (2022) Evaluation of care burden and preparedness of caregivers who provide care to palliative care patients. Palliat Support Care 20: 30-37.
7. Jeba J, Ponissery J, Ramaswamy A, Johnson JR, Thelly AS, et al. (2020) Developing evidence-based clinical guidelines in palliative care for home care setting in India Indian. J Palliat Care 26: 319-322.
8. Bruera E (2004) The development of a palliative care culture. J Palliat Care 20: 316-319.
9. Wajid M, Rajkumar E, Romate J, George AJ, Lakshmi R, et al. (2021) Why is hospice care important? An exploration of its benefits for patients with terminal cancer. BMC Palliat Care 20: 70.
10. Kaur D, Kumar G, Billore N, Singh AK (2016) Defining the role of physiotherapy in palliative care in multiple sclerosis. Indian J Palliat Care 22: 176-179.