International Medical Case Reports Journal

Dovepress
Taylor & Francis Group

Open Access Full Text Article

CASE REPORT

Management of Informal Caregiver Burden in a Case of Primary Cerebral Ewing's Sarcoma: A Case Report

Mattia Gambarin[1], Alessandro Picelli[1–3], Valentina Varalta[1,2], Barbara Santini[4], Lorella Fontana[4], Mirko Filippetti[2,3], Nicola Smania[1,2], Rita Di Censo[1,2]

[1]Neurorehabilitation Unit, Department of Neurosciences, University Hospital of Verona, Verona, 37126, Italy; [2]Neuromotor and Cognitive Rehabilitation Research Center, Section of Physical and Rehabilitation Medicine, Department of Neurosciences, Biomedicine and Movement Sciences, University of Verona, Verona, 37134, Italy; [3]Canadian Advances in Neuro-Orthopedics for Spasticity Consortium (CANOSC), Kingston, ON, K7K 1Z6, Canada; [4]Clinical Psychology Unit, Department of Hospital Medical Management, University Hospital of Verona, Verona, 37126, Italy

Correspondence: Rita Di Censo, Email rita.dicenso@univr.it

Background: Primary cerebral Ewing's sarcoma is a rare and aggressive brain tumor with poor prognosis and limited treatment guidelines. This case describes the assessment and management of caregiver burden for the patient's sister during the rehabilitation pathway.

Case Presentation: A 57-year-old man with primary cerebral Ewing's sarcoma deteriorated rapidly and required care from his 50-year -old sister. Her burden was assessed using the Zarit Burden Interview (ZBI) and the Caregiver Reaction Assessment Scale (CRAS). Interventions included psychological support, relaxation techniques, respite scheduling, and regular multidisciplinary meetings. These efforts reduced caregiver strain and improved perceived support. Patient-Reported Experience Measures (PREMs) showed high satisfaction with inpatient care but revealed gaps in community care continuity.

Conclusion: Caregiver-centred models and improved transitional care should be incorporated into the treatment of rare, high-burden neurological conditions.

Plain Language Summary:

- Informal caregivers of patients with rare neurological cancers face significant emotional and physical burden, which can undermine both the quality and sustainability of home-based care.
- Early systematic assessment of caregiver strain using validated tools (eg, ZBI, CRAS) can guide timely psychological and rehabilitative interventions.
- Multidisciplinary rehabilitation planning that actively includes the caregiver as a partner improves care coordination and enhances caregiver coping capacity.
- Providing structured emotional support and caregiver training enhances adherence to rehabilitation protocols and supports long-term functional outcomes for both patients and caregivers.

Keywords: caregiver burden, informal caregiving, multidisciplinary care, neuro-oncological rehabilitation, primary cerebral Ewing's sarcoma, psychological support

Introduction

Primary Ewing sarcoma of the central nervous system (CNS) represents approximately 1.2% of all Ewing sarcoma cases.[1] Due to its rarity, no standardized treatment protocol exists. Evidence on caregiver burden in rare CNS tumours remains scarce and fragmented, with most studies focusing on more prevalent neuro-oncological conditions. The most common approach involves marginal surgical resection, chemotherapy, and radiotherapy.[1] However, outcomes remain highly variable, influenced by factors such as timing of diagnosis, treatment responsiveness, and tumor aggressiveness.[2–5]

https://doi.org/10.2147/IMCRJ.S562430
Received: 25 August 2025
Accepted: 7 January 2026
Published: 28 February 2026

Despite multidisciplinary management, the prognosis for CNS Ewing sarcoma is poor, with reported event-free survival at 13% and overall survival at 25%.[1]

Recent reports further highlight the prognostic complexity of intracranial Ewing sarcoma, emphasizing anatomical challenges and the narrow therapeutic window associated with these tumors. For instance, Kumar et al[6] described a pediatric cavernous sinus case characterized by rapid progression and limited treatment responsiveness, reinforcing the aggressive nature of intracranial ES and the urgent need for individualized, multidisciplinary strategies.

The extreme rarity of this tumor limits clinical data available, and robust, evidence-based treatment and management guidelines remain unavailable.[3,5] The uncertainty surrounding the illness, coupled with the rapid progression of CNS tumors, can place a significant emotional and practical burden on caregivers. They may have to organize complex treatments and make important medical decisions while witnessing the rapid deterioration of their loved ones' health.

Recognizing caregiver burden early on is crucial to preventing physical and emotional exhaustion, which can compromise both caregiver well-being and the quality of patient care.[7–10]

Cognitive symptoms, particularly confusion, are strongly linked to increased caregiver burden across emotional, financial, and quality-of-life dimensions.[11]

We present a clinical case study of a patient diagnosed with primary central nervous system (CNS) Ewing sarcoma, focusing on the emotional impact on primary informal caregiver. We demonstrate the value of screening tools for identifying caregiver distress and promote their integration into rehabilitation models to support evidence-based strategies that improve care for both caregivers and patients, particularly in rare neuro-oncological conditions.

Case Description

The patient, a 57-year-old religious man, lived with his elderly mother and older sister; his younger sister lived far away. He was childless. In April 2024, he developed balance issues, right leg weakness, and memory loss. A CT scan revealed a left frontal lobe lesion, but the initial biopsy was inconclusive. His condition worsened, requiring neurosurgical hospitalization. He designated his older sister as primary caregiver. Later CT showed a mass invading the corpus callosum and compressing the ventricles. In June, he underwent maximal safe resection; histology confirmed histiocytic Ewing sarcoma. No metastases were found. Transferred to rehabilitation, he deteriorated with fever, apathy, and cognitive deficits, losing decision-making capacity. His caregiver took full charge. Imaging revealed brain abscess, delaying chemotherapy. Ceftazidime and linezolid were administered, causing drowsiness and weakness. After stabilization, rehabilitation and radiotherapy began in late August, improving trunk stability and partial mobility. Severe cognitive deficits persisted, requiring full assistance. A home care plan with chemotherapy and rehab was prepared, but thrombocytopenia and fever emerged before initiation. His condition rapidly declined.

Caregiver Experience

The patient's elderly mother was unable to provide physical or emotional support. Consequently, the primary caregiver was his sister, a 50-year-old religious woman who lived with the family. She was employed and financially stable.

As the patient's condition deteriorated and his cognitive abilities declined, the caregiver experienced increasing emotional and physical strain. She was compelled to assume full responsibility for the patient's daily care and medical decision-making, all while managing her own personal and professional life. The onset of emotional exhaustion, anxiety, and physical fatigue became evident. The caregiver reported emotional distress, including frequent crying episodes and reduced involvement in social and spiritual activities.

To systematically evaluate the extent of the caregiver burden, the Zarit Burden Interview (ZBI)[12] and the Caregiver Reaction Assessment Scale (CRAS)[13] were administered as validated assessment tools. A timeline of the major events is reported in Table 1.

Zarit Burden Interview

The caregiver demonstrated a moderate-to-severe level of caregiver burden, as reflected by a total score of 48 out of 88 on the Zarit Burden Interview (ZBI-22). She reported a profound sense of loneliness and distress related to the patient's behavioral and cognitive changes. Emotional symptoms included frequent crying and difficulty managing emotions. The

Table 1 Timeline of Events and Caregiving

Date (Month/Year)	Event	Details
Apr 2024	Symptom onset	Balance disturbances, right leg weakness, memory loss
Apr 2024	First CT scan	Lesion in left frontal lobe; initial biopsy inconclusive
Jun 2024	Surgery	Maximal safe resection; histology confirmed primary cerebral Ewing's sarcoma
Jul 2024	Clinical deterioration	Fever, apathy, severe cognitive deficits; brain abscess detected; antibiotics initiated
Aug 2024	Rehabilitation admission	Start of multidisciplinary rehab; radiotherapy initiated late Aug
Aug–Sep 2024	Caregiver burden assessment	ZBI and CRAS administered; high burden detected; psychological support started
Sep 2024	Multidisciplinary meetings	Regular video calls involving caregiver and healthcare team
Oct 2024	Discharge planning	Structured home care plan; community physiotherapy planned
Nov 2024	Clinical deterioration and death	Thrombocytopenia, fever; palliative care; patient passed away
Dec 2024	Caregiver follow-up	PREMs completed; caregiver reported satisfaction with inpatient care but noted gaps in community support

caregiver also developed physical symptoms, such as lower back pain, and expressed significant concern about the patient's future.

Caregiver Reaction Assessment Scale

The caregiver reported significant emotional, physical, and managerial strain, with declining well-being, limited personal time, social isolation, and financial stress. Relationships with friends and extended family were affected, though she remained motivated, found meaning in her role, and felt supported by her immediate family. She received individual psychotherapy focused on emotional exploration, coping strategies, and relaxation techniques. To share decision-making responsibilities, remote video calls were held with other family members, overcoming geographic barriers. These multidisciplinary meetings included the physiatrist, neurosurgeon, oncologist, physiotherapist, neuropsychologist, and psychologist, ensuring clear, compassionate communication. The caregiver was actively involved from admission onward. Table 2 summarizes key issues and interventions.

Table 2 Main Caregiver Concerns and Corresponding Interventions

Identified Problems	Actions Taken
Emotional and physical stress: distress, loneliness, irritability, back pain, stress	Psychological support: individual psychotherapy
Sense of responsibility and usefulness: dedication to the family member	Relaxation techniques: meditation, deep breathing
Mutual dependency: centrality in the caregiving role	Structured breaks: promoting respite to manage stress
Impact on social and personal health: reduction in social life and privacy	Social support facilitation and activity encouragement
Family support: satisfaction and feeling of abandonment	Team meetings via video call: doctor, physiotherapist, neuropsychologist, informal caregiver, external relatives

Table 3 Caregiver Management Assessment, Satisfaction and Improvement Areas

Rehabilitation Stay	Continuity of Care and Territory
Positive aspects: full satisfaction with medical staff; positive evaluation of staff courtesy and availability; satisfactory rehabilitation management	Positive aspects: full satisfaction with information received at discharge; full satisfaction with physiotherapy and care management
Areas for improvement: nursing service, catering, socio-recreational activities (fair satisfaction); reception and service organization (low satisfaction with reception and introductory information); hospitality aspects (low satisfaction with catering and hotel services)	Areas for improvement: communication and coordination (low satisfaction); psychological support and reintegration (low satisfaction)

As the patient's clinical condition improved, a home care plan was developed with pharmacological support, physiotherapy, detailed management instructions, and scheduled outpatient visits for ongoing monitoring and treatment.

Patient-Reported Experience Measures (PREMs) Evaluation

Upon discharge, the caregiver received a Patient-Reported Experience Measures (PREMs) questionnaire to complete within one month. After the patient's death, she expressed gratitude for the support received and reported a return to normal life, though she noted: "I was grateful for the care he received, but I wish the community services had been more coordinated". The PREMs assessed support during hospitalization, communication quality, and hospital-to-home transition, with emphasis on continuity of care and physiotherapy. Results showed overall satisfaction with psychological support and positive interactions with doctors and physiotherapists in rehabilitation. However, communication from healthcare staff did not fully meet her emotional and informational needs. Deficiencies emerged in the hospital-to-home interface, including limited information on home care and poor coordination with community services (see Table 3). Although local psychological support was available, the caregiver opted to suspend it and pursue private care. Her feedback highlighted the importance of integrated, empathetic communication and better continuity across care settings.

Discussion

This case underscores the profound impact of rare and aggressive conditions like primary cerebral Ewing's sarcoma on both patients and informal caregivers. The rapid clinical deterioration, cognitive decline, and absence of standardized treatment protocols significantly intensified caregiver burden. These findings align with Au et al,[11] who demonstrated that cognitive symptoms—particularly confusion—are strongly associated with increased caregiver distress across emotional, financial, and quality-of-life domains. Their research on glioblastoma caregivers reinforces that neurobehavioral symptoms, rather than diagnosis alone, are key drivers of caregiver strain.

The challenges described in this case report are consistent with recent reports highlighting the anatomical complexity and narrow therapeutic window in intracranial Ewing sarcoma.[1,5,14] The aggressive clinical course described in cases such as cavernous sinus ES[6] and rapid progression within weeks[3] underscores the emotional and practical strain on caregivers.

Early recognition of caregiver burden is essential to prevent long-term physical and emotional consequences and to sustain home-based care. This case highlights the value of integrating systematic caregiver assessments into oncological pathways, especially for rare neurological tumors. The use of validated tools such as the Zarit Burden Interview (ZBI) and the Caregiver Reaction Assessment Scale (CRAS) enabled a multidimensional evaluation of emotional, relational, and practical stressors. While the ZBI offered a snapshot of perceived burden, the CRAS provided deeper insight into unmet needs.

The caregiver reported emotional exhaustion, anxiety, and reduced social and spiritual engagement—patterns consistent with literature on advanced cancer caregiving. Key predictors of burden include gender, stress levels, anxiety, and loss of autonomy, with communication difficulties and emotional strain being particularly impactful.[15,16] These findings support the need for multidisciplinary caregiver support services that integrate psychological, social, and educational interventions.

The rapid deterioration observed in our case mirrors findings from Kumarasamy et al, who reported 24% mortality within six months in CNS ES patients with low performance status.[5] Similarly, Haveman et al documented markedly worse outcomes in adults compared to pediatric cases, with event-free survival dropping to 13% in patients over 15 years.[1] These data highlight the prognostic complexity and reinforce the urgency of early caregiver support.

Our approach combined individual psychological support, relaxation techniques, multidisciplinary team meetings, and structured discharge planning. Feedback collected via Patient-Reported Experience Measures (PREMs) validated the effectiveness of this strategy, particularly regarding empathic communication, caregiver inclusion in decision-making, and perceived support. However, PREMs also revealed shortcomings in hospital-to-home coordination, especially concerning information clarity and integration with community services. Despite the activation of local psychological support, the caregiver opted for private care, indicating persistent gaps in continuity.

Emerging evidence also advocates for structured training programs tailored to informal caregivers in rare, neurologically impairing conditions.[17–20] These programs, focused on symptom management, communication, and resilience-building, can empower caregivers, enhance coping, and reduce long-term psychological harm. Recent neuro-oncological reports emphasize the role of multidisciplinary tumor boards in managing rare CNS tumors, advocating for inclusion of diverse expertise. While most publications primarily describe clinical and surgical specialists, psycho-oncology guidelines (for example AWMF and APOS) and COSA recommendations[21–23] explicitly call for integrating psychosocial professionals—such as psychologists and social workers—into these boards. This approach ensures systematic distress screening, caregiver support, and proactive planning during treatment transitions.[24,25]

To improve caregiver support, we propose developing tools that assess burden progression following targeted interventions. One strategy involves setting realistic goals with caregivers and evaluating progress during care management. Literature suggests that goal adjustment capacities—such as disengaging from unattainable goals and reengaging with new ones—are linked to lower anxiety, stress, and depression in cancer caregivers.[26] Although not widely used in oncology, Goal Attainment Scaling (GAS) has shown promise in dementia care, enabling caregivers to set and monitor personal goals, with many reporting goal achievements or surpassing.[27] Divergent caregiver-patient goals, especially in advanced cancer stages, [28] further support individualized goal setting.

Ultimately, our findings align with the growing recognition of informal caregivers as "secondary patients" in oncology. Their well-being directly influences the quality and sustainability of patient care, particularly in home settings. Flexible, proactive, and caregiver-centered approaches are essential to improve outcomes for both patients and families. In publicly funded healthcare systems, interventions are typically delivered within formalised care pathways or supported by robust evidence. While patients are formally recognised within the healthcare system, informal caregivers often lack an equivalent status, making access to structured support dependent on explicit evidence or pathway inclusion. This gap is particularly pronounced in rare diseases, where limited literature and the absence of dedicated pathways restrict the systematic involvement of caregivers despite clear needs.

Although this case focuses on primary CNS Ewing sarcoma, the principles of caregiver-centered interventions—such as systematic burden assessment, psychological support, and structured education—may be broadly applicable to other rare CNS malignancies that share unpredictability, rapid progression, and poor outcomes, all of which create sustained psychological stress for caregivers.

Limitations

The caregiver completed PREMs postmortem, possibly amplifying grief-related emotional aspects and limiting balanced evaluation. Additional limitations include the single-case design and the lack of generalisability, as well as the retrospective and post-mortem collection of PREMs. Future studies should adopt longitudinal tracking of caregiver burden during active illness phases to minimize this confounding and capture dynamic changes over time.

Conclusions

This study highlights the urgent need for a structured, multidimensional approach to supporting informal caregivers of patients with rare, aggressive malignancies like primary cerebral Ewing's sarcoma. Integrating validated assessment tools

into personalized care pathways enables healthcare teams to identify caregiver needs and deliver timely, targeted interventions.

Systematic psychological support, empathic communication, and structured education should be embedded in routine oncology practice to reduce caregiver burden and improve care quality. Clear communication and coordinated care are especially vital during the transition from hospital to home.

Future research should focus on scalable, culturally sensitive, and longitudinal support models that formally recognize caregivers as key stakeholders. These models must provide caregivers with the tools, knowledge, and emotional resources needed to manage the evolving challenges of rare neuro-oncological conditions. These strategies should not remain limited to Ewing sarcoma but be adapted for other rare CNS tumors, where unpredictability and poor prognosis similarly demand caregiver-centered, multidisciplinary approaches.

Data Sharing Statement

Data supporting the results of this case report is available from the corresponding author, upon reasonable request, and in compliance with ethical and privacy considerations.

Ethics and Consent Statements

This case report has been prepared following CARE guidelines. The study was conducted in accordance with the principles of the Declaration of Helsinki. Written informed consent for publication of this case report was obtained from the patient and the caregiver. Ethical approval was not required.

Funding

No funding was received.

Disclosure

The authors report no competing interests in this work.

References

1. Haveman LM, Ranft A, Berg HVD, et al. Primary and metastatic intracranial Ewing sarcoma at diagnosis: retrospective international study and systematic review. *Cancers*. 2020;12(6):1675. doi:10.3390/cancers12061675
2. Kim HJ, Kim JH, Park KJ, Park DH, Kang SH. Primary intracranial Ewing sarcoma with an unusual presentation: a case report. *Brain Tumor Res Treat*. 2024;12(2):115–120. doi:10.14791/btrt.2024.0003
3. Dirilenoğlu F, George Moyo MT, Kahraman A. Primary intra-axial Ewing sarcoma of the central nervous system: report of a rare case with literature review. *Surg Exp Pathol*. 2023;6:12. doi:10.1186/s42047-023-00137-x
4. Huguenard AL, Li YD, Sharifai N, Perkins SM, Dahiya S, Chicoine MR. Multifocal primary central nervous system Ewing sarcoma presenting with intracranial hemorrhage and leptomeningeal dissemination: illustrative case. *J Neurosurg Case Lessons*. 2021;1(10):CASE2042. doi:10.3171/CASE2042
5. Kumarasamy S, Garg K, Singh PK, et al. Primary Ewing's sarcoma affecting the central nervous system: a single-center experience and narrative review. *Childs Nerv Syst*. 2025;41(1):46. doi:10.1007/s00381-024-06707-y
6. Kumar A, Rao RN, Raiyani V, et al. Pediatric primary intracranial Ewing's sarcoma involving cavernous sinus: an untamed evil. *Child's Nerv Syst*. 2025;41:282. doi:10.1007/s00381-025-06943-w
7. Pohlig F, Lenze U, Muhlhofer HML, et al. IT-based psychosocial distress screening in patients with sarcoma and parental caregivers via disease-specific online social media communities. *In Vivo*. 2017;31(3):443–450. doi:10.21873/invivo.11081
8. van Roij J, Brom L, Sommeijer D, van de Poll-Franse L, Raijmakers N; eQuiPe study group. Self-care, resilience, and caregiver burden in relatives of patients with advanced cancer: results from the eQuiPe study. *Support Care Cancer*. 2021;29(12):7975–7984. doi:10.1007/s00520-021-06365-9
9. Ramos-Campos M, Redolat R, Mesa-Gresa P. The mediational role of burden and perceived stress in subjective memory complaints in informal cancer caregivers. *Int J Environ Res Public Health*. 2020;17(7):2190. doi:10.3390/ijerph17072190
10. Persson C, Wennman-Larsen A, Sundin K, Gustavsson P. Assessing informal caregivers' experiences: a qualitative and psychometric evaluation of the Caregiver Reaction Assessment Scale. *Eur J Cancer Care*. 2008;17(2):189–199.
11. Au TH, Willis C, Reblin M, et al. Caregiver burden by treatment and clinical characteristics of patients with glioblastoma. *Support Care Cancer*. 2022;30(2):1365–1375. doi:10.1007/s00520-021-06514-0
12. Chattat R, Cortesi V, Izzicupo F, et al. The Italian version of the Zarit Burden interview: a validation study. *Int Psychogeriatr*. 2011;23(5):797–805. doi:10.1017/S1041610210002218
13. Lucchiari C, Bortturi A, Pravettoni G. Caratteristiche psicometriche della versione italiana della Caregiver Reaction Assessment scale. *Giornale di Psicologia*. 2010;4(1):39–48.

14. Chen J, Cheng R, Fan F, et al. Cranial Ewing sarcoma/Peripheral primitive neuroectodermal tumors: a retrospective study focused on prognostic factors and long-term outcomes. *Front Oncol*. 2019;9:1023. doi:10.3389/fonc.2019.01023
15. Wang T, Molassiotis A, Chung BPM, Tan JY. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care*. 2018;17(1):96. doi:10.1186/s12904-018-0346-9
16. Torres-Tenor JL, Bernal-Hertfelder E, Pertejo-Fernández A, et al. Frequency and predictors of caregiver burden among patients with cancer receiving palliative cancer treatment. *Clin Transl Oncol*. 2025;27(9):3827–3832.
17. Theißen T, Ullrich A, Oechsle K, Wikert J, Bokemeyer C, Schieferdecker A. "Being an informal caregiver - strengthening resources": mixed methods evaluation of a psychoeducational intervention supporting informal caregivers in palliative care. *BMC Palliat Care*. 2024;23(1):95. doi:10.1186/s12904-024-01428-0
18. Decosimo K, Drake C, Coffman CJ, et al. Implementation intensification to disseminate a skills-based caregiver training program: protocol for a type III effectiveness-implementation hybrid trial. *Implement Sci Commun*. 2023;4(1):97. doi:10.1186/s43058-023-00475-7
19. Molassiotis A, Wang M. Understanding and Supporting Informal Cancer Caregivers. *Curr Treat Options Oncol*. 2022;23(4):494–513. doi:10.1007/s11864-022-00955-3
20. Badr H, Gupta V, Sikora A, Posner M. Psychological distress in patients and caregivers over the course of radiotherapy for head and neck cancer. *Oral Oncol*. 2014;50(10):1005–1011. doi:10.1016/j.oraloncology.2014.07.003
21. German Guideline Program in Oncology (German Cancer Society, German Cancer Aid, AWMF): S3-Leitlinie Psycho-oncological Diagnostics, Counseling and Treatment of Adult Cancer Patients, Long version 2.0, 2023, AWMF Registration Number: 032051OL, Berlin. 2023.
22. Pirl WF, Fann JR, Greer JA, et al. Recommendations for the implementation of distress screening programs in cancer centers: report from the American Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force. *Cancer*. 2014;120(19):2946–2954. doi:10.1002/cncr.28750
23. Clinical Oncology Society of Australia (COSA). *Guidelines for the Psychosocial Management of Adolescents and Young Adults Diagnosed with Cancer*. Sydney: COSA; 2025.
24. Rogers JL, Wall T, Acquaye-Mallory AA, et al. Virtual multi-institutional tumor board: a strategy for personalized diagnoses and management of rare CNS tumors. *J Neuro-Oncol*. 2024;167(3):349–359. doi:10.1007/s11060-024-04613-6
25. Khalafallah AM, Jimenez AE, Romo CG, et al. Quantifying the utility of a multidisciplinary neuro-oncology tumor board. *J Neurosurg*. 2020;135(1):87–92. doi:10.3171/2020.5.JNS201299
26. Wrosch C, Amir E, Miller GE. Goal adjustment capacities, coping, and subjective well-being: the sample case of caregivers of cancer patients. *J Pers Soc Psychol*. 2011;100(5):934–946. doi:10.1037/a0022873
27. Van't Leven N, de Lange J. The effectiveness of the goal attainment scaling method in family caregiver support: a quasi-experimental study. *Int J Nurs Stud*. 2013;50(5):642–650.
28. Maciejewski PK, Prigerson HG. Identifying goals of care at the end of life: caregiver–patient congruence and its association with outcomes. *J Pain Sympt Manage*. 2023;65(2):e73–e81.