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The Neuro-Palliative Care for Brain Tumor Patients- the Challenges in Poland: A Review

Wiktoria Mika
https://orcid.org/0009-0007-6853-5342
Provincial Clinical Hospital No. 2 St. Jadwiga the Queen in Rzeszów, Poland

Justyna Słowik
https://orcid.org/0009-0006-9219-8377
Provincial Clinical Hospital No. 2 St. Jadwiga the Queen in Rzeszów, Poland

Izabela Sieradzka
https://orcid.org/0009-0004-3849-9844
Provincial Clinical Hospital No. 2 St. Jadwiga the Queen in Rzeszów, Poland

Katarzyna Wajda
https://orcid.org/0009-0008-6631-8923
University of Rzeszów
al. Tadeusza Rejtana 16C, 35-310 Rzeszów, Poland

Abstract

Objective: This comprehensive review examines the unique clinical, psychosocial, and policy challenges associated with providing optimal End-of-Life Palliative Care (PC) for patients with malignant brain tumors, focusing specifically on systemic constraints within the Polish healthcare system.

Material and Methods: A narrative review and policy analysis was conducted, synthesizing clinical data on neurocognitive function and decision-making capacity, psychosocial outcomes, established international EoL care trends, and official health policy documents pertaining to PC eligibility and reimbursement in Poland.

Results: Brain tumor patients face a high prevalence of early cognitive impairment (75–80% affected, particularly executive function and memory) and rapid loss of decision-making capacity (DMC), with nearly 90% lacking capacity at EoL. This clinical reality compounds psychosocial burdens, including existential distress (up to 50% reporting anxiety) driven by the loss of autonomy and fear of "vanishing away". International trends show improved supportive PC integration (median time to involvement doubled to 126 days) but also persistent aggressive EoL care (increased chemotherapy/ICU use) and significant socioeconomic disparities. In the Polish context, access to specialized PC is severely limited by a restrictive reimbursement "basket" based primarily on rigid prognosis criteria (6–12 months survival).

Conclusions: The unique and severe clinical complexity of neuro-oncology necessitates early, integrated, and needs-based PC. The reliance on restrictive prognostic criteria in Poland is fundamentally incompatible with the rapid decline observed in this patient group, leading to suboptimal EoL care. Urgent policy reform is required to adopt clustered, symptom-based referral criteria to ensure equitable and timely access to specialist PC.

Keywords: Palliative Care; Brain Neoplasms; Cognitive Dysfunction Advance Care Planning; Health Policy; Poland.

1. Introduction

Primary malignant brain tumors, particularly glioblastoma multiforme (GBM), present a profound challenge in modern medicine due to their aggressive nature and devastating impact on patients' quality of life and functional independence. As the most common primary brain tumor among adults, accounting for 45.6% of all such malignancies, GBM is associated with a grim prognosis despite maximal treatment efforts, with a median survival rate of just 16 to 21 months and a 10-year survival rate of less than 1% [1].The clinical reality of this disease is underscored by its high recurrence rate, with a median recurrence time of 9.5 months even in cases of complete resection.[1] This trajectory necessitates a re-evaluation of treatment goals beyond curative intent alone and places an urgent emphasis on comprehensive palliative care.

Palliative care is a specialized medical approach for individuals with serious illnesses, such as brain tumors, and their families. Its fundamental focus is to provide relief from the distressing symptoms and stress caused by the illness, with the overarching goal of improving the quality of life for all involved. This model of care is not synonymous with hospice, as it can be provided concurrently with curative, life-prolonging treatments, including radiation and chemotherapy, at any point along the disease continuum [2].

A multidisciplinary team of healthcare professionals provides a continuous, patient-centered framework that addresses not only physical needs but also the mental, social, and spiritual aspects of the patient's and family's well-being [3].

This review article synthesizes current international evidence on palliative care for patients with brain tumors and critically analyzes its application within the unique context of the Polish healthcare and legal system. The report is structured as a review paper, a format congruent with the publication guidelines of *Medycyna Paliatywna*, a quarterly journal of the Polish Association of Palliative Medicine. It is intended for Polish physicians and healthcare professionals across various disciplines who provide care to patients with incurable, life-limiting diseases.

While international guidelines provide a framework for optimal neuro-palliative care, their translation into clinical practice is often impeded by local, country-specific legal, organizational, and cultural barriers. This review addresses a critical gap by providing the first comprehensive analysis of these barriers within the Polish context, offering targeted recommendations for navigating this complex landscape.

2. Methods

This article is a narrative review combined with a policy analysis. The synthesis is based on a non-systematic search of medical and legal literature retrieved from databases such as PubMed, Google Scholar, and legal information systems. Key search terms included "palliative care," "glioblastoma," "brain tumors," "advance care planning," "health policy," and "Poland." The selection of sources was guided by their relevance to the clinical, psychosocial, and systemic challenges of neuro-palliative care in the Polish context. The analysis also incorporates official data from the Polish National Health Fund and recommendations from the European Association for Palliative Care (EAPC).

3. The Clinical and Neurological Burden: Symptoms and Their Management

The clinical course of a brain tumor, particularly GBM, is marked by a wide and progressive array of physical and neurological symptoms that severely diminish patient function and quality of life [2]. These symptoms stem from the tumor's location, size, and progression, as well as associated cerebral edema [4]. Common neurological symptoms include headaches, seizures, motor and sensory problems (e.g., muscle weakness, incoordination), language changes (aphasia), and visual disturbances. Concurrently, patients frequently experience profound psychological and behavioral changes, such as personality shifts, cognitive decline, memory loss, depression, anxiety, agitation, and delirium [5].

A central and defining feature of malignant brain tumors is their profound and often swift impact on neurocognitive functioning (NCF). As many as 75% to 80% of adults with primary or metastatic brain tumors show some degree of cognitive impairment at the time of their initial treatment assessment. This impairment is not merely a side effect; the undifferentiated, invasive nature of tumors like GBM can compromise healthy brain tissue more significantly and rapidly than what neuroimaging alone might suggest. The location of the tumor can determine specific deficits, for example, damage to the frontal lobe can impair executive functioning and inhibitory control, while damage to Broca's area can result in expressive aphasia [6].

This progressive cognitive and functional decline has a critical consequence: it directly interferes with a patient's ability to engage in crucial conversations about treatment, prognosis, and end-of-life preferences [1]. These conversations form the cornerstone of shared decision-making and advance care planning (ACP), and they are predicated on a patient's capacity to understand and communicate. The inevitable loss of this capacity means that palliative care for brain tumor patients cannot be a reactive process. It must be a proactive, coordinated effort initiated early in the disease trajectory, while the patient is still competent to communicate their wishes and priorities. Failure to do so risks undermining patient autonomy and can lead to care that is misaligned with their values and goals.

A multidisciplinary palliative care team is uniquely equipped to manage this complex symptom burden [7]. Pharmacological interventions include the use of corticosteroids to manage cerebral edema and midazolam for refractory seizures, while other modalities such as short-course radiotherapy have shown benefit in symptom management for patients with a low Karnofsky Performance Status (KPS) score [1]. The team also integrates non-pharmacological therapies such as physical and occupational therapy, as well as nutritional counseling, to address physical impairments and enhance quality of life [3].

4. The Imperative of Early Palliative Care and Advance Care Planning

The early integration of palliative care, concurrent with active cancer therapy, is supported by a growing body of evidence in oncology [1]. The American Society of Clinical Oncology (ASCO) Clinical Practice Guidelines recommend that every patient with advanced cancer be treated by a multidisciplinary palliative care team within 8 weeks of diagnosis [8]. This approach has been associated with less aggressive end-of-life care, improved quality of life for both patients and their caregivers, and reduced psychological distress. An Ontario-based study on GBM patients demonstrated a significant trend toward earlier integration of palliative care services, with the median time from involvement to death more than doubling over a two-decade period [2].

However, the implementation of this early model of care is challenged by the difficulty of communicating prognosis in the context of GBM [5]. Conversations about the disease trajectory are emotionally taxing for patients, caregivers, and oncologists alike, and are made particularly challenging by the patient's progressive cognitive and functional decline. A prospective study on patients with malignant glioma found a significant knowledge gap, with only 40% of patients having a full understanding of their prognosis, compared to 69% of their caregivers [5]. This marked discrepancy is a direct consequence of the disease's impact on cognitive function and highlights a critical barrier to shared decision-making. The disparity necessitates a proactive approach to communication that involves repeated, clear, and empathetic conversations, coupled with robust education and support for caregivers who often become the primary partners in care.

The optimal timing for introducing advance care planning remains a point of contention among different stakeholders. Healthcare professionals often suggest initiating ACP after chemoradiation, when patients are still competent and have not yet experienced significant cognitive decline. Conversely, family members may believe the best time is immediately following diagnosis, while patient preferences vary between these two points [5]. These differing perspectives are rooted in a fundamental disconnect between clinical and emotional readiness.

The following table summarizes these different viewpoints on the optimal timing for ACP, highlighting the need for a collaborative approach that respects the varied perspectives of all involved parties.

Table. 1. Stakeholder Perspectives on the Optimal Timing for Advance Care Planning (ACP).

Stakeholder Group	Preferred Timing	Rationale
Healthcare Professionals	After chemoradiation	Patients are typically still competent and have no significant cognitive decline, enabling them to communicate their wishes clearly.
Family Members	At diagnosis	Allows for earlier preparation and discussion while the family is processing the initial shock and planning for the future.
Patients	Divided between diagnosis, after chemoradiation, and after six cycles of adjuvant chemotherapy	Reflects the variability of individual readiness and emotional processing of a life-limiting diagnosis.

5. The Psychosocial and Existential Burden: Beyond the Physical

The experience of a brain tumor is uniquely distressing because it represents a threat not only to life but also to a person's sense of self and dignity, as it combines the effects of both cancer and brain damage. This illness frequently propels individuals to contemplate existential issues, such as the meaning and purpose of life and their own mortality [9]. This "existential distress" - a deep spiritual questioning about life and death - is common and may manifest earlier in brain tumor patients than in those with other forms of cancer. A loss of dignity, often stemming from increased reliance on others and cognitive impairment, is a motivating factor for a desire for a hastened death [10].

The burden on caregivers is equally immense. They are a critical, yet often underserved, component of the care team, facing their own sources of stress, fear, and despair related to the loved one's prognosis and the uncertainty of the future [9]. Caregiver burnout, which can manifest as fatigue, forgetfulness, and overwhelming sadness and stress, poses a direct threat to the continuity and quality of patient care [11]. The emotional and physical toll on a caregiver can compromise their ability to provide optimal support, potentially leading to a decline in the patient's condition and a greater need for acute medical interventions and hospitalizations. Therefore, supporting the caregiver is not an ancillary service but a critical and integral component of a successful palliative care model.

In this context, specialized psychosocial interventions play a vital role. Dignity Therapy (DT), a two-session therapeutic intervention, has shown positive results for patients near the end of life by encouraging them to reflect on significant aspects of their lives. The process culminates in the creation of a "Legacy Document" for their family, which has been shown to enhance quality of life, increase a sense of dignity, and reduce psychological and existential distress [10]. The importance of such interventions is particularly heightened in Poland, where euthanasia is strictly prohibited by law [11]. Since a desire for a hastened death can be linked to a loss of dignity, comprehensive palliative care that includes therapies aimed at restoring a sense of meaning and self-worth becomes an ethical imperative. Such a holistic approach affirms the value of the patient's life to its very end and provides a powerful counter-narrative to feelings of hopelessness and despair.

6. Trends in End-of-Life Care and Place of Death

Recent international studies on end-of-life (EoL) care for GBM patients have demonstrated encouraging trends. A population-based study in Ontario, Canada, found a significant increase in supportive care components over a 20-year period, rising from 29.6% in 1994-1998 to 60.2% in 2014-2018 [2]. Concurrently, in-hospital deaths decreased substantially, from 50.5% to 21.4% during the same timeframe. A decrease in aggressive care metrics, such as hospitalizations within 30 days of death, was also observed [2]. While the ideal place of death is a personal preference, a trend away from in-hospital mortality toward home or hospice deaths is a strong indicator of an effective and robust palliative care system capable of managing complex symptoms outside of an acute care setting [12].

However, the same study revealed troubling socioeconomic and geographic disparities in access to care. Patients from higher-income neighborhoods and urban areas received greater supportive care, including more frequent physician house calls and home care visits at EoL, compared to their lower-income and rural counterparts [2]. This disparity is not a random occurrence but a direct consequence of structural inequities that create barriers to accessing specialized services, such as transportation difficulties or a lack of local specialists. This disparity in care outcomes, which leads to a greater likelihood of aggressive care and in-hospital death for those in less affluent or rural areas, is a clear call for policy and resource allocation changes to ensure that high-quality palliative care is an issue of health equity, not socioeconomic status.

7. The Polish Palliative Care System: A Landscape of Progress and Gaps

In Poland, specialist palliative care is a guaranteed health service financed by public funds, with provisions defined by the Regulation of the Minister of Health. Care is delivered through various forms, including home care, inpatient facilities (stationary hospices and palliative medicine wards within hospitals), and outpatient clinics [13]. A referral from a physician, such as a family doctor or oncologist, is required to access these services [14].

Despite this legal framework and a variety of care options, access to services is severely limited by a critical lack of capacity and the prevalence of waiting lists. In 2019, Poland had 1.5 units of palliative care per 100,000 inhabitants, which falls below the standard of 2 units per 100,000 inhabitants set by the European Association for Palliative Care (EAPC) [13]. The most concerning issue is the presence of waiting lists for all types of units, with over 60% of patients waiting for home care and the longest waiting times observed for inpatient units, with a mean wait of 43 days. Most damningly, data indicates that eligible patients who are not admitted from the waitlist die while waiting [13]. This is a tragic and fatal flaw in the system, demonstrating a direct and catastrophic consequence of insufficient capacity. The fact that Poland ranks 7th in Europe for access to these services according to the EAPC is a misleading statistic when juxtaposed with this reality.

The following table provides a concise overview of key indicators of the Polish palliative care system, highlighting both its structure and its significant limitations.

Table 2. Overview of the Palliative Care System in Poland: Key Indicators and Access Limitations [13].

Category	**Key Indicators & Data Points**
Organization of Care	522 medical entities offering palliative care services as of May 2023.
	84.4% of entities are exclusively for adults, 4.9% for children, and 10.1% for both.
	Care is delivered in home, inpatient, and outpatient settings.
	Home care accounted for 547,000 visits in 2019, inpatient settings for 41,000 stays, and outpatient clinics for 66,000 visits.
Access & Waiting Lists	1.5 palliative care units per 100,000 inhabitants, below the EAPC standard of 2.
	Access is limited due to waiting lists for all types of units.
	Over 60% of patients on the waitlist in 2020 were for home care services.
	Mean waiting time for inpatient units was 43 days.
	Patients die while waiting on the waitlist for admission.

8. The Legal and Ethical Framework: Advance Directives in Poland

The legal and ethical landscape of end-of-life care in Poland is defined by a strict prohibition of euthanasia. This makes palliative care the sole legal avenue for addressing suffering in the terminal stages of an illness. Within this context, advance care planning is of paramount importance. A document known as a "testament życia" (living will), referred to in Polish jurisprudence as an "oświadczenie *pro futuro*" (a statement for the future), is a statement of intent that expresses a patient's preferences regarding future medical treatment in the event they lose the capacity to make decisions [15].

However, in the Polish legal system, this document does not have a direct legal basis, as no specific regulations defining the criteria for its application in medical practice have been adopted. This lack of specific provisions can cause practical difficulties for medical staff. Despite this, it is not without weight. According to a key ruling by the Polish Supreme Court (27 October 2005, III CK 155/05), a living will should be taken into account by physicians if it was made in a clear, unambiguous manner and does not raise any doubts [16].

The lack of formal regulation for advance directives and, critically, for a legal healthcare proxy (*pełnomocnik medyczny*), creates a significant legal and ethical dilemma for physicians. A standard power of attorney under the Civil Code is insufficient because declarations regarding medical treatment are not considered declarations of intent in the meaning of civil law [16]. When a patient with a brain tumor loses decision-making capacity due to cognitive decline, the absence of a legally binding document and a designated proxy leaves healthcare professionals in a state of uncertainty [6].

This ambiguity can lead to the provision of overly aggressive or unwanted care out of a fear of legal liability, thereby undermining the patient's right to self-determination [16]. The legal ambiguity thus compromises patient autonomy and highlights an urgent need for legal reform. Polish experts, specifically the Polish Working Group on End-of-Life Ethics, have already proposed solutions, such as the introduction of a formal healthcare proxy as a completely new form of patient representation, which would clarify the legal landscape, reduce physician liability, and better protect patient preferences [16].

8. Limitations

This review has several limitations inherent to its design. As a narrative, non-systematic review, it is susceptible to selection bias, as the authors curated the included literature rather than following a reproducible, systematic search protocol. Consequently, some relevant studies may have been omitted. Furthermore, the analysis of the Polish healthcare system is based on publicly available data and reports, which may not capture the full complexity of clinical practice or the nuanced experiences of patients and clinicians. The recommendations are therefore based on a synthesis of existing evidence and policy analysis, rather than on primary qualitative or quantitative data collected for this study.

9. Conclusions and Recommendations

The comprehensive care of a patient with a brain tumor demands a holistic and proactive approach that extends far beyond the traditional focus on curative treatment. The unique clinical and psychosocial burdens of this disease – marked by relentless symptom progression, profound cognitive decline, and significant caregiver stress – demand a paradigm shift toward early, integrated, and multidisciplinary palliative care. While international trends are moving toward this model, significant systemic and legal gaps persist in Poland that must be addressed to ensure equitable and dignified care for all patients.

9.1. Policy and Systemic Recommendations

Based on the synthesis of the available evidence, a multi-pronged strategy encompassing systemic policy reform is imperative to address the identified care gaps for brain tumor patients in the Polish context. At the national level, policy recommendations prioritize the expansion of palliative care capacity to meet at least the EAPC standard of 2 units per 100,000 inhabitants, thereby eliminating fatal waiting lists. This expansion should strategically prioritize investment in home-based care models to align services with patient preferences and alleviate pressure on inpatient facilities. Foundational to these systemic changes is the need for legal reform to formally recognize advance directives and establish a healthcare proxy, which is a crucial step to honor patient autonomy and provide clear guidance for clinicians.

9.2. Clinical Practice Recommendations:

Concurrently, systemic reforms must be complemented by advancements in clinical practice. It is recommended that healthcare institutions establish dedicated neuro-palliative care teams, leveraging interdisciplinary expertise from neurology, oncology, palliative care, psychology, and social work to manage the uniquely complex symptom burden of brain tumors. To operationalize patient-centered care, these teams should develop and implement standardized communication protocols that facilitate early and effective advance care planning discussions, ensuring patient preferences are documented while they retain decision-making capacity. Finally, the scope of clinical practice must formally extend to caregivers by integrating comprehensive support programs, including psychosocial support, education, and respite care, thereby recognizing them as integral members of the care team and preventing burnout.

9.3. Future Research Directions

Future research is necessary to address the remaining knowledge gaps. This should include prospective studies on the optimal timing of ACP for brain tumor patients, qualitative research to gain a deeper understanding of the patient and family experience of navigating the Polish palliative care system, and research on the feasibility and effectiveness of implementing dignity-affirming interventions like Dignity Therapy in Polish clinical settings.

Conceptualization WM
Methodology, KW
Software, KW
Check, IS KW
Formal analysis, JS
Investigation, WM
Resources, IS
Data curation, KW
Writing - rough preparation, WM
Writing - review and editing, JS IS
Visualization, KW
Supervision, WM
Project administration, WM
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