https://doi.org/10.37723/jumdc.v17i1.1385

J. Univ. Med. Dent. Coll.2026;Vol.17(1): vii-ix
ISSN (Print) 2221-7827, ISSN (Online) 2310-5542
https://www.jumdc.com

Guest Editorial

Surviving a rare brain cancer without a safety net: The burden of glioblastoma on families in Pakistan

Maha Maqbool [a]

[a] Assistant Professor, Department of Periodontology, Lahore Medical and Dental College, Lahore.
Correspondence:* mahamaqbool21@gmail.com

How to cite this: Maqbool M. Surviving a rare brain cancer without a safety net: The burden of glioblastoma on families in Pakistan. Journal of University Medical & Dental College. 2026;17(1):vii-ix.

A family's experience with a rare disease goes beyond being a medical burden; in many cases, it is very much a personal experience. For me, my father went from being healthy to being ill with no sign of a problem. He worked full-time as a paediatrician, so he had a high level of medical knowledge and experience and had made a lifelong commitment to the profession. Most of the time, he was in the hospital caring for sick children and then at home being a father and devoted to my mother and three daughters. It is hard to explain how sudden the changes in his life were. He would pause while spelling simple words, and conversations became increasingly difficult to keep up with; many times, he couldn't find the right words to convey his thoughts. All of us just brushed these occurrences off because my father worked so much; he had a high volume of working hours, and we all thought everyone got tired. He had been in great physical condition his entire life and had always been the one to help, answer people, and provide healing. So how could anything be wrong with him?

Almost immediately, after a few days of worry and fast-paced back-and-forth between the hospital and the doctor's office, we received an MRI report that stated otherwise. Our family received a diagnosis that would forever change our lives: "Glioblastoma Multiforme WHO Grade IV" [1].

Glioblastoma Multiforme (GBM) is an uncommon, aggressive brain neoplasm originating from the brain. GBM redefined for us what it means to survive, how we care for each other and what it means to have hope. While GBM is considered a rare condition, it currently affects approximately 7 of every 100,000 people. Additionally, GBM is the most common form of primary malignant brain neoplasm. Unfortunately, the median survival after diagnosis is only about 12 to 18 months post-diagnosis, given the availability of many treatment options [2].

For us, the next step was straight foward, it was suggested that we proceed to surgery in which the skull would be opened up, and the surgeon would attempt to get rid of all diseased tissue that can be seen with the naked eye; they refer to this type of surgery as "craniotomy". We felt soothed when the neurosurgeon performed a complete gross resection following a successful procedure that removed all tumors or impacted areas of GBM. Unfortunately, that relief did not last long because there have been no major breakthroughs in the treatment of Glioblastomas in over 2 decades (20 years). The standard treatment protocol for glioblastoma multiforme is referred to as the Stupp Protocol. After surgically excising as much of the glioblastoma (tumor) as possible, patients undergo six weeks of radiotherapy and then begin chemotherapy with Temozolomide [3]. Unfortunately, that is the only standard treatment pathway.

For those diagnosed with an aggressive tumor such as Glioblastoma Multiforme, it is very common for the tumor to return. In addition to returning, there will likely be few treatment options when it does return. Some new treatments, such as Bevacizumab, help cut off the blood supply to the tumor which may slow growth and improve scan results and clinical symptoms. However, the time gained with any new treatment would likely be approximated in months (not years) [4].

Patients in Pakistan also face further challenges with this type of cancer because there are very few clinical trials underway locally as compared to many high-income countries, which are now doing extensive experimental clinical trials as potential avenues to explore for this type of cancer. Knowing there are other countries doing experimental therapies, yet the many patients who are within the scope of Pakistan's boundaries will likely not be able to access them because of distance, and the cost associated with travelling there for care, is heartbreaking [5].

Glioblastoma has also been shown to severely impair the patient's cognition. Of newly diagnosed patients, up to 76% have some degree of neurocognitive impairment, which impacts nearly every function related to cognition - such as memory, attention, executive functioning, verbal fluency, and recall - to some degree [6]. The challenges related to neurocognitive impairment differ for every patient based on the location of their tumor, and may even be exacerbated by the very therapies designed to treat the cancer (e.g., chemotherapy, radiotherapy). Even before patients experience any decline in their physical condition as a result of glioblastoma, there are functional deficits present, which negatively impact their overall quality of life. Recurrence of my father's disease was accompanied by problems in speech (aphasia). This became a major issue for us as a family because communicating with my father was difficult, and he often struggled to find the words he wanted. He spoke much less fluently than he had spoken previously. In addition to impacting our communication with him, his diagnosis and aphasia also isolated him from us and negatively affected his ability to work as a pediatric consultant.

Many people from developing countries, such as Pakistan, feel alone as families of adult patients diagnosed with glioblastoma because they do not have sufficient resources to help them care for their loved one. The limited availability of resources from outside providers does not give any family caregiver support, such as access to physical or speech therapy, and there is no confirmed expectation for neuro-rehabilitation, as the resources for such care are also limited and inconsistent throughout the country. As of 2023, the World Health Organization reports that approximately 27 million people living in Pakistan are disabled in some way; however, there is currently less than one rehabilitation professional per 10,000 disabled people in Pakistan[7]. So, we found ourselves trying to bridge the gap between the need for care and the care actually available, despite lacking proper guidance or formal training to do so.

Glioblastoma may be a fairly uncommon cancer; however, glioblastoma is frequently underrepresented in research and trial activities, especially in developing nations, where patients have few avenues for international collaboration with regard to research efforts. In Pakistan, research on glioblastoma has suffered from a lack of sustained funding and limited access to advanced technologies. The result has been a very small number of studies outside of retrospective analyses being conducted over the past five years[5]. Thus, leaving the tumor biology largely unknown creates substantial limitations regarding potential therapies and opportunities to participate in clinical studies.

The last element, which is about the financial cost of glioblastoma diagnosis in Pakistan, presents a major challenge for patients and their families. Surgical, radiological and chemotherapy options frequently have a high cost for those families who have no means of meeting. Many families are simply unable to access the lifesaving therapies (e.g. temozolomide or modern radiation) they require due to a lack of governmental assistance, with treatment costs usually passed entirely onto patients[8]. Many families cannot cope with large and uncontrolled treatment costs and may be unable to stop treatment prematurely. Public health systems in Pakistan are notoriously underfunded, and advanced treatments, follow-up imaging, and rehabilitative services are unattainable for a vast number of Pakistanis [8].

There are many difficult things about this terminal condition that are not often discussed in a public forum. For 23 months, my family struggled, fought for, and ultimately succumbed to our loved one who passed due to this condition. Bearing the burden of no formal rehabilitation services, we too became speech therapists using the help of online resources for guidance, performing rigorous physiotherapy without the benefit of any trained professionals. The only solace we had was communicating with the patient and other family members around the world, exchanging thoughts and seeking assistance.

For my father, his passing wasn't due to a lack of love or lack of effort towards getting treatment; it is further proof of how difficult it is in Pakistan to live with a rarely diagnosed condition. It is extremely sad and frustrating to lose someone you love because other countries have access to the treatments he needed, but we don't have access here. The story he leaves behind should help drive change in developing countries so they can be part of global glioblastoma research studies. Governments need to invest in the development of healthcare facilities and support for rehabilitation and family caregivers, and recognize those caregivers as vital to the healthcare system. Other areas for government investment include expanding access to radiation therapy and training specialists; increasing public awareness about glioblastoma and other brain tumours; improving access to trials; and supporting those who cannot afford treatment.

I write this message both from a daughter’s perspective and as someone who has been in this situation. Real change in cancer care does not mean just having the numbers that show how many people live through their cancer; it means making sure that no family ever feels alone after being told that their loved one has a serious cancer diagnosis.

ACKNOWLEDGEMENT: None.
CONFLICT OF INTEREST: None.
GRANT SUPPORT AND FINANCIAL DISCLOSURE: None.

REFERENCES:

1. Louis DN, Ohgaki H, Wiestler OD, Cavenee WK, Burger PC, Jouvet A, et al. The 2007 WHO classification of tumours of the central nervous system. Acta neuropathologica. 2007;114(2):97-109.Doi:10.1007/s00401-007-0243-4
2. Irshad HA, Rizvi SB, Bajwa MH, Khalid MU, Shah MM, Enam SA. Epidemiology of glioblastoma in Pakistan: a secondary analysis of the Pakistan Brain Tumor Epidemiology Study (PBTES). Journal of Neuro-Oncology. 2025;171(2):455-62. Doi:10.1007/s11060-024-04872-3
3. Gaillard F, Campos A, Kogan J. Stupp protocol. Radiopaedia.org. Available from:https://doi.org/10.53347/rID-42300 (Accessed 2026 Jan 08).
4. Zaki A, Nida-e-Zehra AA, Jabbar AA. Glioblastoma multiforme with long term survival. Archives of Clinical and Medical Case Reports. 2022;6(4):595-598. Doi:10.26502/acmcr.96550524

5. Abdullah UE, Laghari AA, Khalid MU, Rashid HB, Jabbar AA, Mubarak F, et al. Current management of glioma in Pakistan. Glioma. 2019;2(3):139-144. Doi:10.4103/glioma.glioma_15_19
6. Sekely A, Bernstein LJ, Campbell KL, Mason WP, Laperriere N, Kalidindi N, et al. Neurocognitive impairment, neurobehavioral symptoms, fatigue, sleep disturbance, and depressive symptoms in patients with newly diagnosed glioblastoma. Neuro-Oncology Practice. 2023;10(1):89-96. Doi:10.1093/nop/npac068
7. Zahid Z, Atique S, Saghir MH, Ali I, Shahid A, Malik RA. A commentary on telerehabilitation services in Pakistan: current trends and future possibilities. International journal of telerehabilitation. 2017;9(1):71-76. Doi:10.5195/ijt.2017.6224
8. Tebha SS, Memon SA, Mehmood Q, Mukherjee D, Abdi H, Negida A. Glioblastoma management in low and middle-income countries; existing challenges and policy recommendations. Brain and Spine. 2023;3:101775. Doi:10.1016/j.bas.2023.101775