



"I AM TIRED OF BEING TIRED": PATIENT AND HEALTHCARE PROFESSIONAL PERSPECTIVES ON FATIGUE MANAGEMENT IN PRIMARY BRAIN TUMOUR

Rachael Simms-Moore, Professor Emma Dures, Dr Neil Barua, Professor Fiona Cramp
University of the West of England

Background

Primary brain tumours (PBTs) are abnormal growths that originate in the brain’s own tissues or supportive structures, unlike metastatic tumours which spread from other body sites ¹. They are classified as **lower-grade (WHO I–II)** or **higher-grade (WHO III–IV)**, with the latter typically growing faster and associated with poorer outcomes ^{1,2}. Due to their **sensitive anatomical location** and **complex treatment regimens**, PBTs result in a **high symptom burden** and the **highest number of life-years lost** among all cancers ³. **Fatigue** is one of the most **common, disabling, and poorly managed** PBT symptoms. It is a **persistent, multidimensional** experience involving **physical, cognitive, and emotional exhaustion**, unmitigated by sleep and unrelated to activity levels ^{4,5}. It significantly reduces **quality of life**, limiting the ability to **work, socialise**, and engage in **daily activities** ⁶.

There are **no standardised non-pharmacological interventions** for fatigue in people with PBT, even though **patients often prefer these over medication** ^{7,8}. The **psychological and cognitive effects** of brain tumours further complicate fatigue management ³.

Aim

To explore the experiences, challenges, and strategies used by patients and healthcare professionals (HCP) to understand and manage fatigue in primary brain tumour care.

12,000

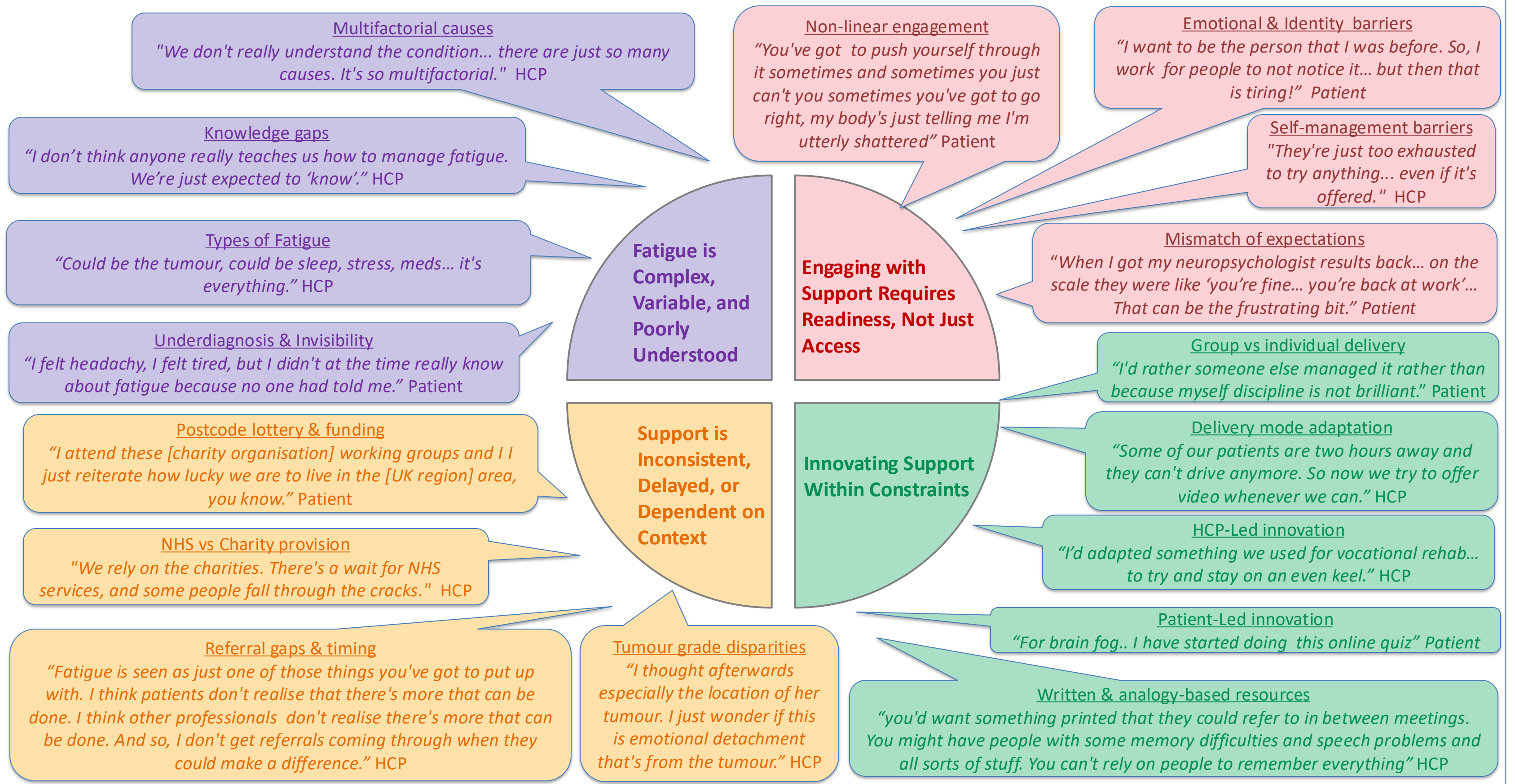
Brain tumours diagnosed every year ⁶

Methods & Participants

Data Collection	Patients N=13	Healthcare professionals N=11	Data Analysis
<ul style="list-style-type: none">1:1 semi-structured interviews.Topic guides developed with input from patient research partners and supervisory team.Participants recruited via brain tumour charities and clinical networks.	<p>Age: 26–68, Mean: 47, SD: 11 Gender: 61.5% F, 38.5% M. Years since diagnosis: 1–14, Mean: 5, SD 4 Tumour grades: 2–4</p> <p>Tumour Types: Anaplastic astrocytoma, Astrocytoma, Glioblastoma Multiforme, Glioma, Oligodendroglioma, Pontine Glioma</p>	<p>Age: 26–58, Mean: 47, SD: 9 Gender: 100% F Years of experience: 2.5–30, Mean: 10, SD: 8</p> <p>Professions: Advanced Clinical Practitioner, Clinical nurse specialist, Rare Cancer nurse, Occupational Therapist, Physiotherapist, Radiographer, Clinical Psychologist</p>	<ul style="list-style-type: none">Data were analysed in NVivo using Braun and Clarke’s (2006) ⁹ Reflexive thematic analysis.336 codes leading to 4 themes and 17 subthemes.

References
1. NICE. Guidance on cancer services: Improving outcomes for people with brain and other CNS tumours. London: National Institute for Clinical Excellence; 2006. 2. Brown TJ, Brennan MC, Li M, Church EW, Brandmeir NJ, Rakaszewski KL, et al. Association of the extent of resection with survival in glioblastoma: A systematic review and meta-analysis. *JAMA Oncol.* 2016;2(11):1460–9. 3. NICE. Brain tumours (primary) and brain metastases in over 16s. NICE guideline NG99. 2021. Available from: <https://www.nice.org.uk/guidance/ng99>. 4. Armstrong TS, Vera-Bolanos E, Acquaye AA, Gilbert MR, Ladha H, Mendoza T. The symptom burden of primary brain tumors: Evidence for a core set of tumor- and treatment-related symptoms. *Neuro-Oncology.* 2016;18(2):252–60. 5. Bower JE, Lacchetti C, Ali D, Barton DL, Bruner D, Canin BE, et al. Management of fatigue in adult survivors of cancer: ASCO–Society for Integrative Oncology guideline update. *J Clin Oncol.* 2024;42(20):[in press]. 6. Cancer Research UK. Brain tumour survival prognosis indicators. 2019. Available from: <https://www.cancerresearchuk.org/about-cancer/brain-tumours/survival>. 7. Day J, Yust-Katz S, Cachia D, Wefel J, Tremont Lukats IW, Bulbeck H, et al. Interventions for the management of fatigue in adults with a primary brain tumour. *Cochrane Database Syst Rev.* 2022;9:CD011376. 8. Higginson IJ. Fatigue in cancer. Oxford: Oxford University Press; 2004. 9. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77–101.

Themes[4] & Subthemes [17]



Conclusion & Implications

- **Fatigue management** in PBT is undermined by **system limitations** and **uncertainty**.
- Patients engage with support in highly **individualised, emotional**, and **evolving** ways.
- HCPs want to improve care, but **structural** and **evidence** gaps remain.
- **Co-designed, evidence-informed** pathways—combining **early screening, streamlined referrals, HCP training, and flexible delivery** are essential to bridge gaps in patient need and provision.
- **Implement routine fatigue screening** with **clear referral guidance**.
- **Co-design** practical **self-management tools** targeting **cognitive** and **emotional needs**.
- **Offer flexible delivery** (telehealth, small groups, printed/analogy resources).
- **Equip HCPs** with **brief, evidence-based training** and PBT specific **toolkits**.
- **Standardise fatigue support pathways** to ensure **equitable access** across regions.

Acknowledgements

Thank you to our four fantastic patient research partners and the many charities who kindly lent their support and guidance in recruiting for this study; **Braintrust, The Brain Tumour Charity, Brain Tumour Research, Tessa Jowell and Black in Cancer.**

Contact

