

"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 cancers³. 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

Methods & Participants

Data Collection

- 1:1 semi-structured
- Topic guides developed with input from patient research partners and supervisory team.
- Participants recruited via brain tumour charities and clinical networks.

Patients N=13

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

Tumour Types:

1. NICE. Guidance on cancer services: Improving outcomes for people with brain and other CNS tumo

Brandmeir NJ, Rakszawski KL, et al. Association of the extent of resection with survival in gliobla

and brain metastases in over 16s. NICE guideline NG99. 2021. Available from: https://www.nice.c

symptom burden of primary brain tumors: Evidence for a core set of tumor- and treatment-relate

et al. Management of fatigue in adult survivors of cancer: ASCO-Society for Integrative Oncology

indicators. 2019. Available from: https://www.cancerresearchuk.org/about-cancer/brain-tumou

management of fatigue in adults with a primary brain tumour. Cochrane Database Syst Rev. 202

thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.

Anaplastic astrocytoma, Astrocytoma, Glioblastoma Multiforme, Glioma, Oligodendroglioma, Pontine Glioma

Healthcare professionals N=11

Age: 26-58, Mean: 47, SD: 9 **Gender**: 100% F Years of experience: 2.5-30, Mean: 10, SD: 8

Professions:

Advanced Clinical Practitioner, Clinical nurse specialist, Rare Cancer nurse, Occupational Therapist, Physiotherapist, Radiographer, Clinical Psychologist

ondon: National Institute for Clinical Excellence; 2006. <mark>2.</mark> Brown TJ, Brennan MC, Li M, Church EW,

idance/ng99 **4**. Armstrong TS, Vera-Bolanos E, Acquaye AA, Gilbert MR, Ladha H, Mendoza T. The

D011376. **8.** Higginson IJ. Fatigue in cancer. Oxford: Oxford University Press; 2004. **9.** Braun V, Clarke V. Us

ival 7. Day J, Yust-Katz S, Cachia D, Wefel J, Tremont Lukats IW, Bulbeck H, et al. Intervention

s. Neuro-Oncology. 2016;18(2):252–60. 5. Bower JE, Lacchetti C, Alici Y, Barton DL, Bruner D, Canin

pdate. *J Clin Oncol*. 2024;42(20):[in press]. **6.** Cancer Research UK. Brain tumour survival prognosi

Data Analysis

- Data were analysed in NVivo using Braun and Clarke's (2006) 9 Reflexive thematic analysis.
- 336 codes leading to 4 themes and 17 subthemes.

Themes[4] & Subthemes [17]

Multifactorial causes

"We don't really understand the condition... there are just so many causes. It's so multifactorial." HCP

Knowledge gaps

"I don't think anyone really teaches us how to manage fatigue. We're just expected to 'know'." HCP

Types of Fatigue

"Could be the tumour, could be sleep, stress, meds... it's everything." HCP

Underdiagnosis & Invisibility

"I felt headachy, I felt tired, but I didn't at the time really know about fatigue because no one had told me." Patient

Postcode lottery & funding

"I attend these [charity organisation] working groups and I I just reiterate how lucky we are to live in the [UK region] area, you know." Patient

NHS vs Charity provision

"We rely on the charities. There's a wait for NHS services, and some people fall through the cracks." HCP

Referral gaps & timing

"Fatigue is seen as just one of those things you've got to put up with. I think patients don't realise that there's more that can be done. I think other professionals don't realise there's more that can be done. And so, I don't get referrals coming through when they could make a difference." HCP

Non-linear engagement

Engaging with

Access

Support Requires

Readiness, Not Just

Innovating Support

Within Constraints

Fatigue is

Complex,

Poorly

Variable, and

Understood

Support is

Inconsistent,

Delayed, or

Context

Dependent on

Tumour grade disparities

"I thought afterwards

especially the location of her

tumour. I just wonder if this

is emotional detachment

that's from the tumour." HCP

"You've got to push yourself through it sometimes and sometimes you just can't you sometimes you've got to go right, my body's just telling me I'm utterly shattered" Patient

"They're just too exhausted to try anything... even if it's offered." HCP

Self-management barriers

Mismatch of expectations

Emotional & Identity barriers

"I want to be the person that I was before. So, I

work for people to not notice it... but then that

is tiring!" Patient

"When I got my neuropsychologist results back... on the scale they were like 'you're fine... you're back at work'... That can be the frustrating bit." Patient

Group vs individual delivery

"I'd rather someone else managed it rather than because myself discipline is not brilliant." Patient

Delivery mode adaptation

"Some of our patients are two hours away and they can't drive anymore. So now we try to offer video whenever we can." HCP

HCP-Led innovation

"I'd adapted something we used for vocational rehab... to try and stay on an even keel." HCP

Patient-Led innovation

"For brain fog.. I have started doing this online quiz" Patient

"you'd want something printed that they could refer to in between meetings. You might have people with some memory difficulties and speech problems and all sorts of stuff. You can't rely on people to remember everything" HCP

Cancer.

Conclusion & Implications

- Fatigue management in PBT is undermined by system limitations and
- 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**
- **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; Brainstrust, The Brain Tumour **Charity, Brain Tumour Research,** Contact Tessa Jowell and Black in



