UNDERSTANDING THE VARIATION IN BRAIN AND CENTRAL NERVOUS SYSTEM SURVIVORSHIP OUTCOMES AND MORBIDITIES

WE ARE MACMILLAN. CANCER SUPPORT

J Shield[1], J Flynn[1], T Welchman[2], E Drage[2], M Gibbs[2], C Edson[2], A Brodbelt[3], VP Collins[4], D Greenberg[5]
[1]Macmillan Cancer Support; [2]Monitor Deloitte; [3]The Walton Centre NHS Foundation Trust; [4]University of Cambridge; [5]National Cancer Registration Service

Background

'Routes from Diagnosis' (RfD) links and analyses routinely collected cancer registry and HES data to map out the cancer journey for whole cohorts of patients over up to 7 years after diagnosis. This approach brings together information on survival, morbidities and demographics, painting a detailed picture of survivorship.

Applying these methods to brain and central nervous system tumours, we aimed to investigate the heterogeneity of survivorship outcomes within this grouping of tumour types, including the prevalence of 'meaningful' morbidities treated in inpatient care.

Method

Clinical experts and data analysts collaborated to map out cancer journeys for 8,762 patients diagnosed with brain/CNS tumours in England in the years 2003-4.

Brain/CNS tumour types are less uniform in impact when compared to other common cancers, and thus within the RfD analysis it was important to distinguish between morphology groupings with meaningfully different behaviours. In order to do this, as ICD-10 coding for brain/CNS cancers is known to be poor, the team enlisted both the advice of the clinical expert team and NCRS who used additional information from the National Brain and CNS Tumour Registry to assign morphology types to patients in the RfD dataset.

Within the brain/CNS tumour grouping, tumour morphology largely determines survival length and morbidity prevalence. A survivorship outcome framework (Figure 1) was therefore applied separately to cohorts with glioblastomas, meningiomas and spinal and cranial nerve sheath tumours in order to investigate the differences in survivorship between these groups.

Morbidity prevalence was also compared with a random sample of age- and sex-matched patients with an inpatient record.

Results

63.8% and 87.2% of patients with meningiomas and nerve sheath tumours respectively survived 7+ years post-diagnosis (Figure 1b, c), whereas 78.7% of glioblastoma (1a) patients lived less than 12 months.

Figure 2 draws a comparison between the morbidity burden ratios of the glioblastoma, meningioma and nerve sheath tumour populations alive at one year who experienced other inpatient morbidities, and the proportion of an inpatient, non-cancer comparison group who experienced the same morbidities.

Of those patients with meningiomas or nerve sheath tumours who lived to 12 months, both groups experienced significantly higher levels of nervous system morbidities than a comparison group (e.g. inflammatory CNS diseases, episodic disorders and paralytic syndromes); however, meningioma patients also experienced significantly higher levels of endocrine (ratio of 2.4), respiratory (1.5), musculoskeletal (2.9) and circulatory (2.0) morbidities.

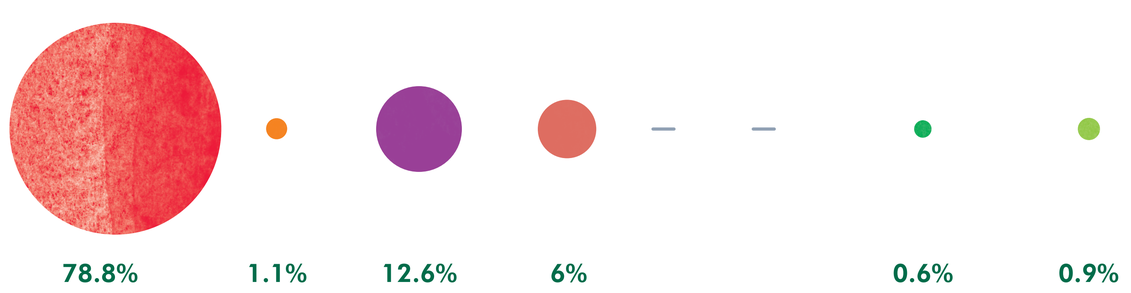
Figure 2: Comparison of brain tumour patients and a non-cancer comparison population living with morbidities at 1 year after diagnosis

		Endocrine	Respiratory	Musculoskeletal	Circulatory	Nervous
Prevalence among comparison population		3.5%	3.6%	0.5%	11.5%	1.2%
Cancer morbidity burden (ratio)	Glioblastoma	1.6	1.6	3.7	1.8	19.8
	Meningioma	2.4	1.5	2.9	2.0	14.1
	Nerve sheath	0.8	1.0	1.5	1.2	17.1

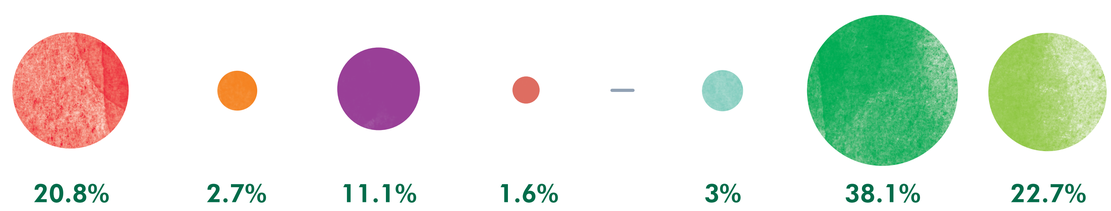
■ Significantly higher proportion in cancer patients with p ≤0.001

Figure 1: Graphical view of simplified RfD survivorship outcome framework for the three most common brain/CNS tumour types

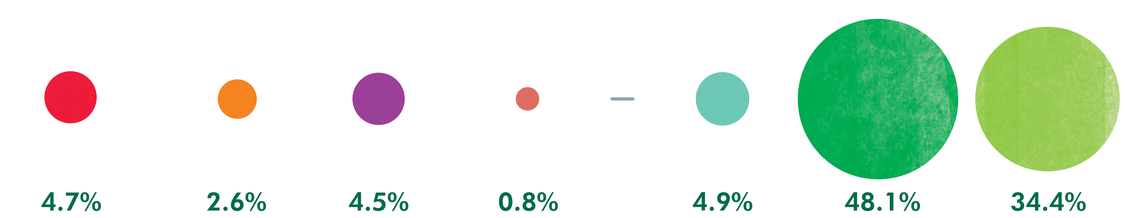
a. Glioblastoma



b. Meningioma



c. Nerve sheath



Limited survival

● **Group 1**
0-12 months survival

Limited - moderate survival

● **Group 2**
1-7 years survival with cancer complications

● **Group 3**
1-7 years survival with other inpatient morbidities

● **Group 4**
1-7 years survival with no other inpatient morbidities

On-going survival

● **Group 6**
7+ years survival with cancer complications

● **Group 7**
7+ years survival with other inpatient morbidities

● **Group 8**
7+ years survival with no other inpatient morbidities

Note: 'Cancer complications' includes additional primary cancers and recurrence. 'Other inpatient morbidities' includes relevant complications as defined by the clinical advisory group; Colour coding indicates severity of disease, from most severe (red) to least severe (green). Group 5 is not applicable to the brain/CNS tumours simplified survivorship outcomes framework.

Conclusion

If long-term patient outcomes are to be understood and improved, it is essential to make the greatest use possible of readily available data generated and held by the NHS. This study demonstrates the value of analysing routinely collected data to unpick variations in survivorship outcomes within tumour types. The use of a non-cancer comparison group also allows the variation in and burden of morbidity to be better understood, which in future could enable more tailored care pathways to be put in place.

'Stark survival figures, high morbidities, and high healthcare costs for patients with glioblastoma demonstrate clearly the terrible nature of this disease for patients and their carers. The data presented argue forcibly for clear coordinated care pathways for patients, and for a massive increase in research funding to improve quality of survival.'

Mr Andrew Brodbelt, Consultant Neurosurgeon

In partnership with:

NCIN national cancer intelligence network
Using information to improve quality & choice

Monitor Deloitte.

For further findings, see Routes from Diagnosis: the most detailed map of cancer survivorship yet

bit.ly/macmillanrfd