Portrayals of narcolepsy from 1980 to 2020: a descriptive analysis of stigmatizing content in newspaper articles

Neurological disorders can often be misconstrued in society, with the potential to impact on how those affected are viewed and considered. This study is quite novel and considered the influential role of the media as a source of health information, and indeed, misinformation, aiming to describe how narcolepsy is portrayed in newspapers. The researchers collected 257 newspaper articles and reviewed these, coding for themes around sensationalistic titles, negative language, stigmatising content, stereotypical content, disclosure or diagnosis, accurate diagnosis, describing a person with narcolepsy as dangerous, symptoms, and diagnostic and treatment services. Findings illustrate that narcolepsy is often misrepresented in the media, right from the outset with article titles often being sensationalistic (10.9%). Of concern was that 10.5% also had inappropriate, negative or outdated language, which does not help with the social understanding of what is already a complex, often misunderstood disorder. For example, 5.1% of articles described people with narcolepsy as being dangerous and only 16.7% described identifiable symptoms, despite this public information being important for those yet undiagnosed in terms of attending for medical assessment. This is within the content of 30.4% of articles referring to the presence of an accurate diagnosis. Only 2.1% of articles referred to diagnostic and treatment services, illustrating a lost opportunity to provide accurate public information on how narcolepsy is diagnosed and treated. This is of particular note given the long periods of delay in diagnosis that are well-established in the literature. The paper provides a variety of recommendations to improve the media portrayal of narcolepsy with a view to breaking down stigma around the condition.

Is memory impaired in narcolepsy type 1?

Understanding of the physical and cognitive impacts of narcolepsy remain to be an emerging science with a degree of focus around impact over recent decades. Medrano-Martínez et al. (2022) set out to explore the issue of memory deficit in those with narcolepsy with cataplexy (narcolepsy type 1 – NT1) given the potential impact of cognitive impairment in health-related quality of life. They used standardised neuropsychological tests with participants with NT1 (n=12) and had a control group for comparison (n=14). Tests included questionnaires on verbal learning, sustained attention, information processing speed, sleepiness, depression. Results showed that people with NT1 scored significantly higher on the Epworth Sleepiness Scale than the control group. Additionally, using the Beck depression inventory – II, there were significant differences between groups, with the NT1 demonstrating high scores. Task performance was shown to be impaired with sustained attention was required, but that those with NT1 could compensate here if the task duration is short. Memory test results showed similar performance across both groups, but that the NT1 group recall an average of five less items than the control group – the data here is inconclusive and merits investigation with larger numbers of participants. Given the impact of depressive symptoms on cognitive performance, it was not conclusive as to whether narcolepsy or depressive symptoms may have an impact on subjective memory. Further research is warranted on a larger scale to further understand the impact of NT1 on cognitive functioning, including a consideration as to whether the tools being used for assessment are sufficiently sensitive for a subgroup of people who may have a degree of compensatory skills.

Post-acute blood biomarkers and disease progression in traumatic brain injury

This study highlights the potential of blood biomarkers such as those used in the acute phase of traumatic brain injury (glial fibrillary acid protein and neurofilament light) to characterise traumatic brain injury in the chronic phase. This is based on the hypothesis that these proteins may be biomarkers of continuing neurodegeneration. The researchers examined the relationship between biomarkers, imaging changes and functional outcome at around 8 months and greater than five years
after traumatic brain injury. This was a two-centre study that enrolled 204 patients. In total, there were 211 blood samples from people with TBI and 35 from controls. For imaging, there were 134 patients at 8 months and 38 at greater than five years. The study identified that there are persistent and temporarily distinct elevations in Glial fibrillary Acid Protein (GFAP) and neurofilament light (NFL) biomarkers up to 13 years after traumatic brain injury. In particular, NFL levels at 8 months predicted white matter volume loss at greater than five years. Elevations in GFAP and NFL correlated closely with microstructural injury in grey and white matter on imaging. This study highlights the potential for blood biomarker levels at different time points in the chronic phase to identify traumatic brain injury survivors at high risk of progressive neurological damage. The study warrants further extension to confirm the findings and to establish the potential use of such biomarkers as standardised practice in risk assessing and responding to progressive neurological damage.

**Impact of Seizures and Status Epilepticus on Outcome in Patients with Aneurysmal Subarachnoid Hemorrhage**

Seizure activity, and the variations in its presentation and nature, are a recognised complication from aneurysmal subarachnoid haemorrhage (aSAH) and have been correlated with unfavourable outcomes and therefore may have a predictive value. This study, undertaken in Zurich, identified 245 patients with aSAH over a four-year period and identified 76 who experienced acute symptomatic seizures; 39 experiencing seizures at onset, 18 experiencing acute seizures, and 19 experienced acute nonconvulsive status epilepticus (NCSE). Analysis identified that acute symptomatic NCSE is an independent predictor of unfavourable outcome. Additionally, there was significant association between all seizures and NCSE with higher Fisher grade. Acute seizures/NCSE were not found to be associated with unfavourable outcome in patients with a high Hunt-Hess grade, but were significantly associated with unfavourable outcome in patients with a low Hunt-Hess grade, identifying their predictive value in this regard. The study highlights the necessity to consider the impact of seizures on level of conscious in the ictal and postictal phases, particularly in terms of how this may impact on detecting neurological deterioration and the potential to lead to a delayed diagnosis of further complications associated with aSAH (e.g. secondary infarction).

**Utilization of Brain Tissue Oxygenation Monitoring and Association with Mortality Following Severe Traumatic Brain Injury**

This study aimed to describe use of brain tissue oxygen (PbtO2) monitoring following severe traumatic brain injury (TBI) and any links with mortality. Using a retrospective cohort approach in the US, patients from US trauma centres were reviewed from across an eight-year period who had PbtO2 monitoring. Results show that 35,501 patients had an intracranial pressure monitor placed, of whom 1,346 additionally had a PbtO2 monitor placed. The latter group had a 31.1% mortality rate in comparison to 33.5% for those with ICP monitor placement alone. The development of acute respiratory distress syndrome was comparable in both groups. PbtO2 monitoring alongside ICP monitoring, in comparison to ICP monitoring alone, was associated with a decreased in-hospital mortality, a longer length of stay, and a similar risk of ARDS. In addition, the study revealed that use of PbtO2 varies significantly and is not consistent with patient characteristics. The findings support that efforts to prevent secondary brain injury that include monitoring and responding to brain tissue oxygenation measurement, can be effective in reducing mortality. A limitation of the study is that it did not review the interventions to reduce secondary brain injury, other than the placement of PbtO2 monitoring was associated with reduced mortality. Given the reduction in mortality, the authors conclude that larger multicentre trials are needed to explore the finer details of the interventions that lead to reduced mortality. The findings highlight the importance of PbtO2 monitoring and its potential to lead to interventions that reduce secondary brain injury.
References


