



Health inequalities: Epilepsy

Introduction

Epilepsy is one of the most common (and best documented) serious brain disorders¹. Mortality is increased in people who have epilepsy with a pooled relative risk of death of 3.3 (95% CI 2.83, 3.92) compared to the general population².

Prevalence and risk factors

A systematic review and meta-analysis reported that the pooled prevalence estimate of epilepsy in people with learning disability from a range of countries based on 38 studies was 22.2% (95% CI 19.6–25.1)³. Prevalence increased with increasing level of intellectual disability. Prevalence was lower in people with Down syndrome with the pooled estimate from 13 studies being 12.4% (95% CI 9.1–16.7), decreasing to 10.3% (95% CI 8.4–12.6) following removal of 2 studies focusing on older people. Prevalence increased with age in people with Down syndrome and was particularly prevalent in those with Alzheimer's/dementia. For England, GPES data for 2017/18 indicate that 17.9% of patients with learning disability had an active diagnosis of epilepsy and were on drug treatment for epilepsy compared to 0.6% of those with no recorded learning disability⁴.

Impact on people with learning disabilities

In England, it has been reported that 'convulsions and epilepsy' accounted for more than 40% of all emergency admissions for ambulatory care sensitive conditions (ACSCs) for people with learning disabilities, accounting for 6,000 admissions and 28,000 bed days per year⁵. Epilepsy or convulsions has also been identified as an important and to some extent potentially preventable cause of death of people with learning disability⁶.

Evidence suggests that people with learning disabilities and epilepsy have a substantially increased risk of mortality, particularly where seizures are ongoing⁷. Over the period 1993 to 2010, Sudden Unexpected Death in Epilepsy (SUDEP) was the second most common cause of death among adults with epilepsy and learning disabilities on the Leicestershire Intellectual Disability Register⁸.

People with epilepsy may have elevated mortality from external causes such as accidents including drowning⁹. In 2013, a teenager with learning disabilities drowned following a seizure at a Short Term Assessment and Treatment Unit, having been left alone in the bath despite having epilepsy¹⁰. In relation to quality of life, people with learning disability may have qualitatively different concerns about their epilepsy to carers or clinicians, such as wetting themselves during a seizure, or feeling embarrassed if having a fit when out¹¹.

Healthcare and treatment

NICE (2012) guidelines state that: 'The recommendations on choice of treatment and the importance of regular monitoring of effectiveness and tolerability are the same for those with learning disabilities as for the general population'¹². However, the management of epilepsy in people with learning disabilities presents unique challenges, such as the possibility of misdiagnosis due to the misinterpretation of behavioural, physiological, syndrome-related, medication-related or psychological events by parents, paid carers and health professionals¹³.

Research has begun to consider how best to manage epilepsy in people with learning disability, for example by considering whether nurse-led care may lead to improvements in management¹⁴. However, there are significant gaps in the evidence regarding service responses to managing epilepsy in people with learning disabilities including a lack of research regarding the use of epilepsy care plans, seizure diaries or risk assessments¹⁵. Also, whilst self-management interventions have the potential to improve outcomes for people with learning disability and epilepsy¹⁶, little is known about the effectiveness of educating people with learning disability about their epilepsy. However, the feasibility of conducting a RCT of an epilepsy picture booklet to address the information and self-management needs of people with learning disabilities and epilepsy has been established¹⁷.

Problems associated with epilepsy may be compounded by a lack of access to appropriate healthcare. People with learning disabilities and epilepsy may receive suboptimal care¹⁸. There is evidence that care delivery is fragmented in some areas, leading to significant disparity and inequality of care across the UK for adults with a learning disability¹⁹. Access to specialists is inconsistent, with geographical distribution of expertise being termed a 'postcode lottery' within the UK²⁰.

Social determinants

In the general population, there is some evidence that socio-economic factors (such as deprivation and occupation) are associated with both the development of epilepsy and the health outcomes of people with epilepsy^{21 22 23}. These factors have not been systematically investigated in people with learning disabilities.

Resources

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