

Final Report

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Title of Project: Optimisation of seizure management: the costs of epilepsy in Australia and the potential benefits of improved seizure control

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Please note: This is a modification from the original project proposal, titled: "Optimisation of first seizure management: a retrospective data linkage analysis". Due to the impacts of COVID-19 on the Department of Health and Human Services, linkage data from DHHS were unable to be extracted within the intended time frame. The linkage project is still underway, and we look forward to sharing the results of this linkage project when it becomes available.

In the meantime, we are pleased to share the results of another important epilepsy research project undertaken with the support of the Brain Foundation.

This was in collaboration with researchers from Monash University Central Clinical School, Monash University School of Public Health and Preventive Medicine, and The Florey Institute. There was also funding support from an Australian Government Medical Research Future Fund Frontier Health and Medical Research Program Stage One grant (MRFF75908).

Summary

Approximately 45.9 million people worldwide have active epilepsy. Studies show that compared to people without epilepsy, people with epilepsy have significantly higher use of healthcare services, and are more limited in terms of educational, income, and employment opportunities. All these factors have a substantial impact on people with epilepsy, their families, and the wider community.

Many studies, including The Global Burden of Disease (GBD) studies published in *The Lancet*, evaluate the impact of epilepsy on an individual's quality of life using a measurement called 'disability-adjusted life years' (DALYs). However, DALYs do not provide any information about the impact that a disease has on a person's ability to work. Known as 'productivity loss', this arises from illness-related unemployment, days off work, and premature death. Productivity loss is a crucial consideration in the evaluation of the overall burden of disease. The productivity adjusted life year (PALY) is conceptually similar to the DALY, but instead of capturing disease-related quality of life loss, it captures disease-related productivity loss. PALY is a more refined method for capturing productivity loss than those used in previous health-economic studies, as it allows the loss to be understood across various age-sex brackets in society.

We constructed life table models to simulate the burden of epilepsy on working age Australians. The life table models were divided into males and females, and into 5-year ago categories, from 15-19 years old through to 65-69 years old (i.e., the average working lifetime). We then filled the life table models with specific data for each age-sex bracket

from national published data sources. These included Australian Bureau of Statistics, National Health Survey, The World Bank, Australian Institute of Health and Welfare, and Deloitte's Access Economics. We then followed up each age-sex bracket until age 70 years or death, whichever came first. To resemble the real world as accurately as possible, we assumed that 70% of the group with epilepsy had controlled epilepsy, i.e. successfully achieved freedom from their seizures, and 30% had uncontrolled epilepsy, i.e., were experiencing uncontrolled seizures.

Findings

In 2017, there were approximately 17.5 million Australians aged between 15-69 years. Of those, approximately 101,646 had epilepsy. We found that:

- Overall, slightly more females (5.84 per 1,000) than males (5.80 per 1,000) had epilepsy.
- The age-sex bracket with the highest number of people with epilepsy (prevalence) was females aged 50-54 years (9.57 per 1,000 had epilepsy).
- For males, those in the 60-64 years old age bracket had the highest prevalence of epilepsy (8.54 per 1,000).

With follow-up until age 70 years (e.g., a 30-year old was followed up for 40 years; a 60-year old was followed up for 10 years), or death:

- There were 14,053 excess epilepsy-related deaths. Put another way, if those with epilepsy no longer had epilepsy, 56.1% of these deaths would be avoided.
- The proportion of epilepsy-related deaths were greatest in the 15-19 years age bracket for both males and females.
- These excess deaths translated to 78,143 years of life lost. This equates to 0.8 years of life lost per person due to epilepsy.
- Epilepsy was estimated to reduce PALYs by 146,202 over a working lifetime. This would equate to A\$32.4 billion (US\$22.1 billion) of lost GDP.
- The proportion of epilepsy related PALYs lost was greatest in the 25-29 years age bracket for males, and 15-19 years age bracket for females.
- Australians with epilepsy were estimated to incur A\$4.1 billion (US\$2.8 billion) in excess direct healthcare costs.
- The proportion of epilepsy-related direct healthcare costs were greatest in the 65-69 years age bracket for both males and females.

We found that compared to other common diseases, epilepsy exerts a far greater impact on years of life lost and productivity loss per person.

TABLE 1: THE BURDEN OF EPILEPSY IN COMPARISON WITH OTHER CONDITIONS

Other conditions	Years of life lost	Productivity adjusted life years lost
Those with DIABETES, compared to those without diabetes, experience:	3%	10.5 – 11.6%
Those with HIGH BLOOD PRESSURE, compared to those without high blood pressure, experience:	1.2%	2.4%
Those who SMOKE, compared to those who do not smoke, experience:	4.2%	6.0%

Those with EPILEPSY, compared to those without epilepsy, experience:	5.8%	25.8%
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Once we had a good understanding of the differences in outcomes between those with and without epilepsy, we were able to run 'hypothetical' scenarios and determine the impact that even small improvements in seizure freedom might bring.

We found that if seizure freedom in the epilepsy cohort improved by 5% from its current baseline of 70%, i.e. up to 75%, and this level of seizure freedom was maintained up to the end of the follow-up period (i.e., age 70), there would be:

- A\$533 million (US\$364 million) reduction in healthcare costs.
- Prevention of 811 excess deaths, 3,961 years of life gained, and 17,438 PALYs saved, equating to A\$3.9 billion (US\$2.6 billion) in GDP retained over the working lifetime of this cohort.

If seizure freedom were improved by 10% from the current baseline, i.e., up to 80%, there would be:

- A\$1.1 billion (US\$729 million) reduction in healthcare costs.
- Prevention of 1,633 excess deaths, 7,953 years of life gained, and 39,967 PALYs saved, equating to A\$7.8 billion (US\$5.3 billion) GDP retained over the working lifetime of this cohort.

Unanswered Questions

Future studies may involve the creation of 'dynamic' life table models. This will allow people to enter the epilepsy cohort over time (i.e., incidence data may be included), and allow seizure state to change over time, reflecting improvement or worsening of seizure control.

What these research outcomes mean

- This study clearly demonstrates the major costs to society due to epilepsy-related productivity loss.
- This provides very important data for community organisations to advocate for better supports for people diagnosed and living with epilepsy, to help them return and remain in the workforce and to be able to fully participate in society.
- It is also useful information for government and health policy makers as it captures the significant impact of chronic neurological disease on society. This may be taken into account in future policies and budget allocations. In addition, this study shows that older people had the highest proportion of epilepsy-related healthcare expenditure. Therefore, a detailed review of healthcare utilisation and implementing measures to reduce this need may curb this expense.
- These data could be used by clinicians as it highlights the need for optimal seizure control. A focus on more rapid epilepsy diagnosis, treatment initiation, and active pursuit of seizure control may be an effective strategy to reduce the overall burden of epilepsy.
- Finally, a relatively small improvement in seizure freedom, by 5% or 10%, may result in substantial improvement in outcomes and costs. This may incentivise researchers, institutions, and government to invest in the development of new, more effective interventions or medications to better manage this common and devastating disease.

