The costs of epilepsy in Australia: a productivity based analysis

Briefing Document

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SEPTEMBER 2020
REPORT NO.1 / VERSION NO.1
FOREWORD

This report is a summary of a published study (see below) targeted to opinion leaders, decision makers within state and federal governmental departments, and service providers. This study was performed as part of a research project (The Australian Epilepsy Project, AEP, https://epilepsyproject.org.au/) proposed to the Australian government Medical Research Future Fund (MRFF) Frontier Health and Medical Research initiative. This project will collect, curate, and integrate multi-modal data sets including advanced imaging, neurocognitive assessments, and genetic profiles, and use artificial intelligence techniques to formulate the AEP Report – a comprehensive clinical decision support tool to assist clinicians in the fast and accurate diagnosis and optimal treatment of epilepsy. By doing so, the AEP aims to render at least 10% further people with epilepsy as seizure free (that is, no further seizures); the health economic results of this are presented by this research study. As part of this project, it was necessary to demonstrate the significant health economic impact of this proposed management of epilepsy in the Australian context. Knowing the lifetime impacts of epilepsy are extremely important to inform resource allocations for health and support services and to reduce the burden to society.

This document provides an overview of what the research study was about, what the researchers did, what was found, and how the information can be used. It does not provide the detailed data collected for the analysis or the analysis itself (a request can be made to the study authors, see contact details back page).

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ACKNOWLEDGMENTS

We would like to acknowledge the support of the Australian Government Medical Research Future Fund Frontier Health and Medical Research Program Stage One grant (MRFF75908) and the Victorian Government Operational Infrastructure Support Grant. We also would like to acknowledge the wonderful multidisciplinary team for the Australian Epilepsy Project who have collaborated to bring this study to fruition, in particular the Chief Investigator Professor Graeme Jackson from the Florey Institute of Neuroscience and Mental Health.

We also wish to thank Dr Loretta Piccenna at Monash University for her expertise and guidance in developing this document.
EXECUTIVE SUMMARY

- Epilepsy exerts a considerable economic and societal burden in Australia.
- We built a life-table model using 2017 Australian epilepsy-related data from multiple sources (please see references).
- We found that compared to those without epilepsy, those with epilepsy aged 15-69 years, followed until age 70, were predicted to have over 14,000 excess deaths, A$4.1 billion (US$2.8 billion) excess direct healthcare costs, 78,000 years of life lost, and to experience a substantial impact on work productivity.
- All these costs combined to an equivalent GDP loss of more than A$32.4 billion (US$22 billion). Further, this substantial burden rested mainly on younger people.
- Promisingly, improving seizure freedom by 10% would result in A$1.1 billion (US$729 million) in reduced healthcare costs, prevent 1,633 epilepsy-related deaths, and equate to A$7.8 billion (US$5.3 billion) retained due to improvements in work productivity.
- These findings once again highlight the substantial impact of epilepsy, but optimistically, also show that small improvements to seizure freedom that may greatly improve this burden.
THE COSTS OF EPILEPSY IN AUSTRALIA: A PRODUCTIVITY-BASED ANALYSIS

WHAT IS THIS RESEARCH ABOUT?

Approximately 45.9 million people worldwide have active epilepsy. Studies show that compared to people without epilepsy, people with epilepsy have a significantly higher use of healthcare services. Their education and income/employment are also significantly affected, which in turn has an impact on society.

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, they 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 informs the loss across various age-sex brackets in society.

We constructed a life table model to simulate the burden of epilepsy on working age Australians. We used relevant features to inform the model to take into account the different demographic groups in society, including sex (male and female) and age, divided into 5-year age brackets (from 15-19 years old through to 65-69 years old). The main outcomes of interest included epilepsy-related healthcare costs, deaths, and productivity losses. We also modelled the health and economic benefits that might result from modest increases in seizure freedom rates. Seizure freedom refers to patients with epilepsy who no longer experience seizures.

Important definitions or terms for the study

- **Productivity loss** – used to describe illness-related unemployment, underemployment, sick days off work, and premature death that removes people from the workforce earlier than they otherwise would leave.
- **Productivity adjusted life year (PALYs) lost** - measures the difference in ‘productivity’ in the cohort with a disease versus the cohort without that disease. PALYs can be adjusted overtime for individuals as their disease improves or worsens, allowing a more accurate capture of the true burden of disease.
- **Years of life lost (YLL)** - measures the difference of ‘years of life lived’ in the cohort with a disease versus the cohort without that disease.
- **Labour force participation** - this describes the proportion of people in society who are currently working and how much they are working, for example, part time or full time.
- **Life table modelling** – an epidemiological modelling approach that allows researchers to allocate the overall burden of disease into predefined age-sex brackets. For example, males aged 15-19, or females aged 40-44. This allows a more comprehensive and sophisticated understanding of the impact of disease across various demographics in society.
- **Gross domestic product (GDP)** – the total value of goods and services produced in a country. In this study, we divided the total GDP by the number of equivalent full-time workers in Australia. This allowed us to work out what an individual worker contributes to the economy.
WHAT DID THE RESEARCHERS DO?

We created life table models for Australians aged 15-69 years with epilepsy, with a follow up until age 70 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., were not experiencing seizures, and 30% had uncontrolled epilepsy, i.e., were experiencing ongoing seizures despite medical interventions. We matched the relevant data inputs to each group respectively. We then re-simulated this model, assuming the group no longer had epilepsy. Differences in outcomes between these groups were attributed to epilepsy. The outcomes measured included epilepsy-related excess deaths, years of life lost, PALYs lost, and direct healthcare costs. Data inputs for these models were extracted from published Australian general population and epilepsy-related data (2017) from multiple sources, including the:

- Australian Bureau of Statistics (ABS) and National Health Survey data for information regarding mortality, workforce statistics, and productivity measures.
- World Bank data for Australian economic information, for example, GDP values, and the currency value of A$ and US$.
- Australian Institute of Health and Welfare data, regarding health expenditure in Australia.

WHAT DID THE RESEARCHERS FIND?

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 would be followed up for 40 years; a 60-year old would be 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.
Epilepsy exerts a far greater impact on years of life and productivity per person than other common diseases. The table below demonstrates the burden of epilepsy compared to other common conditions.

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

<table>
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<th>Other conditions</th>
<th>Years of life lost</th>
<th>Productivity adjusted life years lost</th>
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<tr>
<td>Those with DIABETES, compared to those without diabetes, experience:</td>
<td>3%</td>
<td>10.5 – 11.6%</td>
</tr>
<tr>
<td>Those with HIGH BLOOD PRESSURE, compared to those without high blood pressure, experience:</td>
<td>1.2%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Those who do SMOKE, compared to those who do NOT smoke, experience:</td>
<td>4.2%</td>
<td>6.0%</td>
</tr>
<tr>
<td>Those with EPILEPSY, compared to those without epilepsy, experience:</td>
<td>5.8%</td>
<td>25.8%</td>
</tr>
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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 several different scenario analyses. This involves adjusting certain factors within the model and seeing what effect these ‘hypothetical’ scenarios have on the outcomes. We were particularly interested on 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.
HOW CAN YOU USE THIS RESEARCH?

▪ 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 considered in the future development of 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.

▪ For clinicians these findings highlights the need for interventions targeted towards younger aged demographics. 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, organisations, and government to invest in the development of new, more effective interventions (for example, the Australian Epilepsy Project) or drugs to better manage this common and devastating disease.
REFERENCES


KEYWORDS

Epilepsy, Productivity, Health service research, Cost effectiveness, Health economics.
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