Guidelines for the Reporting of Neuro-Epidemiological Studies

Background and rationale

At the First International Congress on Clinical Neuroepidemiology (ICCNE) that took place in Munich in August 2009, an open discussion amongst a panel of experienced researchers described approaches to "bridge the gap" between neuroepidemiological research and practice. One of the key themes that emerged was that there were issues with the reporting of neurological research and this was a reason for gaps between evidence and practice for both clinicians and health policy decision makers.[1] The most common type of health policy research seeks to describe or characterize health and healthcare delivery across an entire population or system, or system of care within subpopulations. This type of policy research is critical in the evaluation of a healthcare delivery system, examining how the system is functioning for patients, clinicians or hospitals and identifying problems or opportunities to improve healthcare delivery. Descriptive epidemiological studies are particularly useful for estimating prevalence, incidence, morbidity and mortality for studies where global health is of primary concern.[2] Information from such studies may be used to quantify levels of disability and to compute disability adjusted life-years (DALY) and quality adjusted life years (QALY). DALY and QALY type metrics are particularly useful for Global Burden of Disease and Injuries (GBD) type studies. These kinds of outcomes are particularly important in health policy research as they are relevant to patients, providers, and payers as they allow some kind of value and importance to be determined.[3] Neurological diseases such as stroke, Alzheimer's disease and dementia are becoming more prevalent as the world's population ages,[4,5] and are major causes of disability. [6] The conduct of health policy research in these types of neurological disorder has been hampered by poor reporting of the key information required.

Unfortunately, many descriptive epidemiological studies were not instigated for the purpose of health policy research, particularly nationally representative data used to derive population estimates. Typically, GBD type studies and other similar types of policy research are reliant on the best available data to them. Often key information that is relevant to health policy research is not collected, which severely limits the potential insights that could be obtained from the work. This project aims to devise some guidance, based initially on stroke, with the ultimate objective of producing a set of quality criteria and comparable reporting guidance specifically for common neurological disorders. Stroke was selected as the initial neurological disorder to investigate in order to form the basis of this neurological reporting guideline because it is a clinical priority for neurology, and it is one of the highest ranked diseases in terms of burden in the most recently published Global Burden of Disease and Injuries 2010 project.[5]

Project objectives

1. Collate and summarise the existing literature on the principles of reporting both clinical and methodological aspects of incidence and prevalence studies of stroke ;

2. Produce a draft set of items and principles that exemplify the reporting of incidence and prevalence studies of stroke;

3. Consider the extent to which these principles have been followed by published incidence and prevalence studies of stroke and thereby identify how rigour may be lost and how existing reporting could be improved;

4. Using a Delphi technique synthesise expert input into utility of these draft items extracted in (2) and extend the scope of these items in order to accommodate other common neurological disorders;

5. Using an interdisciplinary panel of experts to further revise the draft checklist items obtained in (4) in order to devise a more definitive set of criteria for reporting standards of neuroepidemiological studies.

6. Disseminate outputs to interested parties (including journal editors and neurological societies).

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References

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