Assessing acquired brain injury in Ireland

Anne MacFarlane et al report on a prevalence study of ABI in general practice

THE PREVALENCE OF ACQUIRED BRAIN INJURY (ABI) in Ireland was assessed in a recent study as part of a partnership between NUI Galway and Acquired Brain Injury Ireland (ABIIR), which responds to the needs of people with acquired brain injury (ABI) in Ireland.

ABI has been defined as “damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease.” These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment. It includes traumatic brain injury, haemorrhage, brain tumours, hypoxic brain injury and infection.

Adverse impacts of brain injury can include behavioural and emotional issues, such as depression, inability to empathise with others, aggression, etc. It can also impact on a person’s memory and ability to rationalise and make sound judgements. In addition, it can impact on a person’s physical abilities such as mobility, speech and other senses. This can have a significant impact on their personal and social lives, leading to loss of employment, marital breakdown, and the breakdown of other established relationships.

Given the lack of specialist and rehabilitation services for ABI, people with ABI are often living and cared for at home and left to rely on community level services, including GPs. The partnership between NUI Galway and ABIIR was established because ABIIR wanted to establish whether GPs could provide prevalence data on ABI. Following a series of meetings, a prevalence study of ABI in general practices in Co Mayo was planned with specific objectives to establish whether GPs are aware of patients with ABI aged 18-65 in their practices, able to provide prevalence data on ABI in patients aged 18-65 and able to provide data on age, gender and patient diagnosis. The authors of the study also planned to analyse the prevalence of ABI from any available data from GPs.

Study

Ethical approval was obtained from the research ethics committee of the College. The questionnaire consisted of one page establishing the practice name, the number of GPs working in the practice and the practice patient population. Next, a filter question inquired as to whether the GPs were aware if there were any ABI patients in their practice population.

They were then further asked to subdivide these patients into different categories depending on the type of ABI acquired and to provide information on the patient’s age, gender and age at diagnosis.

Names and addresses for GPs in Co Mayo were obtained from the HSE Primary Care Unit in Galway. There were 59 general practices in total.

The questionnaire and accompanying materials (information leaflet, consent form, personalised letter and prepaid envelope for the return of questionnaire) were sent out in late July 2007. Questionnaire reminders were organised based on the Dillman criteria.

Calculation of the point prevalence for ABI was undertaken based on the number of known reported ABI cases within the estimated age-specific patient population of those aged 18-65 years. The 95% confidence interval...
for ABI prevalence was also determined. Both descriptive (frequencies, means, standard deviations) and inferential statistical analyses (Pearson’s χ² and one-way ANOVA) were performed in SPSS for Windows (version 14.0).

Results

Overall, 59 general practices received the questionnaire. Nineteen practices (response rate of 32.2%) replied to the survey. The main reasons documented for non-response during fieldwork were that GPs were too busy to take part and received too many requests to take part in research projects. Of our respondents, 57% were rural and 38% were single-handed. A total of 16 practices indicated they knew of people with ABI in their practice population, while two stated there were no cases of ABI affiliated with their practice. One further practice indicated not knowing whether there was someone with ABI in their patient population.

The total estimated patient population reported by the 19 respondent GPs was approximately 50,360. The mean patient population per practice was 2,833; the median practice size was 3,000. According to 2006 census data, 62% of the Mayo population was aged between 18 and 65 years. Applying this percentage to the reported estimated patient population within the respondent practices, there were approximately 31,030 people of the target age group (18-65 years) in the practices who participated in the survey.

A total of 57 patients with ABI were reported to be known to the practices. The number of known ABI cases per practice ranged from one to 11 in the 16 practices that reported cases. The overall distribution of ABI cases for all the practices is presented in Table 1.

Based on the estimated population aged 18-65 years in the respondent practices (31,030), the age-specific prevalence of ABI was estimated to be 183.7 per 100,000. The 95% confidence interval (CI) for the prevalence of ABI is 139.2-237.9 per 100,000.

For all ABI types except tumour, males appeared to be over-represented, though this difference was not statistically significant (Pearson χ² test p = 0.31).

Twenty-six (45.6%) patients attended a general practice located in urban settings, with the remaining 31 people with ABI (54.4%) being noted by GPs from rural areas. Pearson χ² testing revealed statistically significant differences in ABI type according to patient location (p = 0.006); patients with ABI are significantly more likely to reside in a rural area.

The mean age for patients with ABI was 44.5 years (SD = 13.4; 95% CI: 40.9-48.1) whereas the mean age at being diagnosed with ABI was 37.21 years (SD = 15.5; 95% CI: 33.1-41.3). Four people incurred their brain injury at young ages (four, seven, 14 and 17 years), while the remaining cases occurred in people at least 18 years of age.

Discussion

Acquired brain injury is a very large problem in Ireland and abroad. This patient group often lacks access to adequate services. This is due, in part, to a lack of reliable prevalence data.

The purpose of the study was to conduct a prevalence study of ABI through general practices in Co Mayo. Key findings are that GPs are in possession of the information that was sought and are able to identify patients with ABI in their respective practices. The age-specific prevalence of ABI in Co Mayo for those aged 18-65 years was 183.7 per 100,000 (95%CI: 139.2-237.9 per 100,000). Upon extrapolating the age-specific ABI prevalence obtained in this study to the target population of all 18-65 year olds in Co Mayo (76,300), the estimated magnitude of ABI is approximately 140 people (95% CI: 106-182) in this age group. ABI was found to be more common in males, to be principally due to trauma, and to be more prevalent in rural areas. These findings reflect a similar epidemiological profile to that reported in previous studies.6,7

The research reported here is a good example of university-community partnership with benefits for primary care. The expertise of a community-based organisation about a specific condition (ABI) and the research expertise of primary care academics were combined, in a collaborative manner, to design and complete a piece of empirical research relevant to local health and social care needs.

The research is small scale with a low response rate. This is explained by the fact that the research was conducted during a summer holiday period but, also, because there are difficulties with response rates in research involving GPs who are often dealing with a high volume of requests to participate in research. However, the research is a step in the direction of a much-needed, larger and interdisciplinary programme of research that involves the ABI community as experts and collaborators.

References on request

Acknowledgements

Funding from the Health Research Board Summer Scholarship scheme (July-August 2007) and from the Centre for Excellence in Learning and Teaching, NUI Galway.

We are grateful to our respondents and our colleagues, including Prof Andrew Murphy, Brian Buckley (NUI Galway) and Imelda Walsh Worrell (Acquired Brain Injury organisation). Thanks also to Breda Kelleher and Mary Byrne for their assistance in the preparation of this paper.