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Nurses' use of a defined competencies framework to support adults with Epilepsy and intellectual disability-Findings from the EpAID study

Fiona Irvine

University of Birmingham, UK

The World Health Organisation defines intellectual disability (ID) as "a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development". Epilepsy is the most common medical illness in people with IDs. Compared to the general population with epilepsy, individuals with an ID and epilepsy have an increased seizure frequency, higher frequencies of multiple antiepileptic drug use and side effects, higher treatment costs, higher rates of mortality and a greater incidence of behavioural problems.

In the UK, Epilepsy Specialist Nurses (ESNs) with enhanced expertise in the management of epilepsy, offer a range of services to patients with epilepsy, including patient assessment, medication management, ordering and interpreting investigations and providing education, support and counselling to patients and families. However, most people with ID and epilepsy do not receive services from an ESN even though anecdotal evidence suggests that ESNs may help to improve outcomes and reduce the costs of care for adults with epilepsy and an ID.

The Royal College of Nursing has developed a series of competency frameworks for nurses, including the Learning Disability Epilepsy Specialist Nurse Competency Framework, that aims to improve outcomes for adults with an ID and epilepsy. We set out to establish whether the development of a nurse-led approach to managing epilepsy in adults with an intellectual disability, based on this RCN competency framework improved outcomes and lowered costs of care for people with epilepsy and ID.

We undertook a cluster randomised controlled trial to assess the impact on costs and outcomes of the provision of learning disability nurses working to the RCN competency framework.

The trial took place in 17 community ID clinical teams across England, Scotland and Wales and involved 312 adults with an ID and epilepsy (the participants). Eight sites randomly allocated to the intervention arm recruited 184 participants and nine sites allocated to treatment as usual recruited 128 participants. After completing baseline assessment of participants, we trained the

nurses in the intervention arm on the use of the competency framework and they subsequently worked with the participants following the guidance outlined in the competency framework. Nurses in the control arm, received minimal training and then followed their existing management approach for participants. All nurses in the study completed a daily diary in which they recorded the activities that they undertook with the participants. The trial intervention (or control) lasted a minimum of 24 weeks after which time; we followed up participants for a 4-week period, when they completed a range of questionnaires and a qualitative interview. We undertook an economic evaluation in tandem with the study.

Overall, the results of the trial indicated that, in terms of clinical outcomes, the competency framework was no better than treatment as usual. For those with a mild or moderate ID the results suggested that use of the framework might have been associated with a slight reduction in the severity of their seizures, as noticed by somebody providing care for them. The economic analysis suggested that, in general, the competency framework intervention resulted in a small reduction in quality of life but saved money.

The EpAID clinical trial is the first controlled trial to test the possible benefits of a nurse-led intervention for epilepsy in adults with an ID. It suggests that nurses with experience in ID and epilepsy could be well placed to deliver or facilitate the epilepsy management recommended for adults with an ID by the relevant clinical guidelines.

Speaker Biography

Fiona Irvine qualified as a Registered Nurse from the Hammersmith Hospital School of Nursing in 1984 and went on to work in Mid Wales as a District Nursing Sister and latterly, a Macmillan Clinical Nurse Specialist in Palliative Care. During this time, Fiona discovered her love of teaching and having completed her Master of Science Degree in Health Promotion and Health Education, she took up her first academic post, leading a specialist practice community nursing programme in North Wales. Whilst working as a lecturer, following on from this work, Fiona became involved in several funded research studies, which led to her securing her first professorial appointment in 2007. Fiona held senior posts in universities in North Wales and the North West of England before joining the University of Birmingham in March 2014 as Head of Nursing. Since taking up the post, Fiona has been leading the reorganisation of nursing and its relocation to the main building of the College of Medical and Dental Sciences.

e: f.e.irvine@bham.ac.uk