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Setting the agenda for neurological nursing: strategic directions

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Abstract

This paper explores a range of issues related to neurological care. The scope and scale of neurological conditions is described in order to illustrate disparities in research funding and care delivery as compared with cancer and cardiovascular disease. Financial implications, ethical issues and health service development are outlined as a context for the state of the art of neurological nursing. Areas for potential neurological nursing research are identified. Finally, it is argued that policy and research must be linked if neurological care, research and education are to receive greater resource allocation.

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What this paper adds:

- Adds a further stage to Delorio et al.'s (2004) 'theory-then-research' continuum; that of 'clinical implementation'.
- Identifies specific areas for future research in neurological nursing.
- Argues that European standards of care for endstage neurological care need to be established and offers a way forward to accomplish this.

1. Introduction

In March 2005, the Department of Health (England) launched a National Service Framework (NSF) for Long-Term Conditions for care of persons with a neurological disorder including brain and spinal injuries but also used the document to comment more generally

*Tel.: +44 141 330 5498; fax: +44 141 330 3539. *E-mail address*: l.n.smith@clinmed.gla.ac.uk. on long-term disability. This paper is a contribution to a wider debate on the allocation of resources within a health service battling conflicting demands in the face of an increasingly older population. No attempt has been made to cover all aspects of every issue raised. Rather, a broad-stroke approach has been taken in an attempt to increase awareness and interest in those less familiar with neurological nursing. Finally, the paper has been written largely within a European context with only passing reference to elsewhere.

2. Context of neurological nursing

Neurological disorders 'constitute a large and increasing share of the global burden of disease' (WHO, 2004). In the International Classification of Diseases (ICD) neurology has the highest number of conditions listed (MacDonald et al., 2000). Within the ICD classification lie a large number of uncommon and different diseases, many of which are chronic (e.g. multiple sclerosis—MS); some of which are acute (e.g. meningitis); some which

will be the result of sudden and catastrophic trauma (Sullivan, 2005); and few are totally curable (Hewer, 1997). Neurological disease is a major cause of disability accounting for a large percentage of those <65 years who are severely disabled (Hewer, 1997). Whatever we know in terms of the prevalence of neurological disorders, it is likely to be only the 'tip of the iceberg' as so many conditions go unreported either because they are common (e.g. headache) or are stigmatized (e.g. epilepsy) (MacDonald et al., 2000). With heart disease, cancer and stroke rated as 1, 2 and 3 in the mortality stakes in industrialized societies, disorders of the nervous system, when taken together, 'account for more hospitalization, more long-term care and more chronic suffering than nearly all other disorders combined' (Cowan and Kandel, 2001). Yet the resources for neurological care in terms of finance and manpower are disproportionately less when compared with cancer and cardiovascular disease (Pendlebury et al., 2004).

In reviewing the literature for this paper, one key message emerged very quickly; that is in most places in the world, the available resource in terms of neurological care is inadequate in the face of global need (WHO, 2004). The variation in neurological services is such that in western societies, we see 1–10 neurologists per 100,000 population while in other parts of the world, there may be no or only a marginal presence (WHO, 2004). Thus neurological care is a neglected area across the globe.

2.1. Search strategy

The search strategy for this paper is detailed in Table 1 and is included as evidence of the lack of depth in the nursing literature in the neurological field.

2.2. Scope and scale of neurological conditions

If the scope and scale of neurological conditions is investigated, we find there are no accurate figures for neurological disease in the UK (The Neurological Alliance, 2002), Europe (The Neurological Alliance, 2002; WHO, 2004) or the USA (Cowan and Kandel, 2001), only estimates and 'best guesses'. In the USA, approximately 50% of all healthcare is related to chronic conditions and accounts for 80% of total healthcare costs (Greenwood, 2001). Of that 50%, neurological damage is responsible for almost 40% of those most disabled (Greenwood, 2001). In the UK, neurological conditions are responsible for 20% of all hospital admissions (Department of Health, 2005). Further, it is estimated that 350,000 people have a neurological condition in the UK that requires help for most of their daily living activities while a further 1

million are disabled by their condition (The Neurological Alliance, 2002).

In light of the poverty of information surrounding global neurological resources. WHO and the World Federation of Neurology surveyed 106 countries and three territories to produce the 'Atlas Country Resources for Neurological Conditions (WHO, 2004). The Atlas acknowledges that they were reliant on key individuals to collect data and that some data may be incomplete or inaccurate. Nevertheless, it is arguably the most comprehensive index of neurological resources to date. World-wide and at the European primary care level, epilepsy, headache and cerebrovascular disease including stroke are the three most frequently reported neurological conditions (WHO, 2004). However regional variations exist, for example in Africa, where the three most frequently reported neurological conditions in primary care are epilepsy, neuropathies and headache (WHO, 2004).

Stroke is the most common neurological disorder across the European Union (Sudlow and Warlow (1997); the third most common cause of death in industrialized countries; and is the most important cause of morbidity and long-term disability in Europe (The European Stroke Initiative Executive Committee and EUSI Writing Committee, 2003). However, the burden of stroke in comparison to cancer and coronary heart disease (CHD) is under-estimated because stroke's chronic nature often means the problem is hidden in the community (Smith et al., 2004a; Wolfe, 2000). In 2002 (Parliamentary Assembly, 2002), it was estimated that there were at least 330,000 people living with spinal cord injury (paraplegia and tetraplegia) in Council of Europe states, with approximately 11,000 new cases annually. It is thought that 40-50% of these injuries were road traffic accidents with most occurring at a young age. In the UK, 300 per 100,000 are believed to have Progressive Neurological Disease (PND) of which the two most common are MS and Parkinson's disease (Ward et al., 2003).

3. Financial considerations

Health services generally seek to obtain 'value for money' and provide effective, efficient, efficacious care that produces or is capable of producing an intended result equitably. Advances in diagnostics and treatment are leading patients with neurological conditions to live longer (Amsters et al., 2005) with resulting increases in financial cost to families, to nations' healthcare systems and to social services (Cowan and Kandel, 2001). In Europe, the annual cost of Parkinson's disease is estimated to be €781 million in Germany, €321 million in France; €106 million in Sweden and €219 in the UK (EuroPa-European Network for Parkinson's Disease,

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