An Overview of Neurological Disorders in Wales

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Key Words

Neurological disorders, incidence and prevalence •
Commissioning • Wales

Abstract

This pragmatic work was undertaken to assist commissioners of health services in Wales in their planning for future provision of services for neurological and neurosurgical patients. A literature search, which was carried out to ascertain the epidemiology of neurological and neurosurgical disorders in Wales, revealed limited epidemiological surveys of patients in Wales, while other literatures although outdated were still relevant. More recent national reports, published by professional bodies and patients' organisations, were also identified. These disorders were also grouped according to their aetiology and symptoms into 13 groups. Using all the available literature, total estimates of annual incidence and point prevalence of these disorders were arrived at. We can conclude that approximately 5.8% of the population in Wales are affected by neurological and neurosurgical disorders that include headaches, traumatic and infectious diseases of the nervous system.

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Introduction

There are a large number of neurological disorders; some are very common and dealt with by specialties other than neurology and neurosurgery. The majority of stroke patients in the UK never come into contact with a neurologist, and patients with multiple problems, often the elderly, are usually looked after by care-of-the-elderly physicians, even when there is a neurological component such as Parkinson's disease and stroke [1]. Other core neurological and neurosurgical disorders, whilst rare, when aggregated constitute a significant part of the National Health Service (NHS) work. Around 200 people in a population of 100,000 are likely to develop a specific condition such as Parkinson's disease each year, and only 3 in a population of 100,000 experience a traumatic spinal injury every year [2]. Neurological and neurosurgical conditions account for 10% of visits to accident and emergency departments, and are the third most common reason for attending a family doctor [3]. In Wales in 2001/02, diseases of the nervous system constituted 2.3% of all-causes finished consultant episodes and up to 13% of all GP referrals in 2000 [4].

An estimated 17,500 people across Wales need help with activities of daily living as a result of a neurological condition, and 42,500 people care for someone with a neurological condition [3].

A literature search was carried out for seminal reports and publications on the frequency of neurological, neuromuscular and neurosurgical cases, in an attempt to estimate the total burden of these disorders. This work was undertaken to assist commissioners in planning for neurological and neurosurgical services in Wales. This paper presents an overview of the estimated frequency of these disorders as reported by various national and international publications and databases.

Two of the key measurements that are normally used in descriptive epidemiology are the prevalence and incidence of a disease [5]. The prevalence measures the number of current cases of a disease in a defined population at a given time and place. The incidence, on the other hand, is the number of new cases occurring in a defined population, a given place and for a given time interval, usually per year. For rare disorders data may have to be accumulated over several years to be able to state an incidence with an acceptable precision.

Both rates require the precise case definition and ascertainment of all cases of the disease in the target population and this is not always feasible or logistically possible. The population also need to be precisely defined, as many of these disorders, some of which are genetic, vary according to ethnicity and are affected by population mix.

Another term that describes prevalence is the lifetime prevalence, which is the proportion of persons manifesting a disorder during the period of their life up to the survey date; usually this is described as per 1,000 of the population at risk, but it has been reported here per 100,000 to help comparison with other frequency measures and provide meaningful data for the commissioners and providers of health services [6]. Lifetime prevalence depends on the age distribution of those we study, and it is very likely to increase with age. It also requires a strong assumption that the age-specific incidence does not alter with time and cohort. This is probably plausible for Huntington's disease but not many other neurological disorders.

Methodology

Literature search was carried out for seminal publications and databases on the incidence and the prevalence of neurological, neuromuscular and neurosurgical disorders. Sources included: (1) general medical databases – Medline and Embase, integrated bibliographic text-based search and retrieval databases containing journal citations and extracts; (2) Social Care – Social Care Online, an extensive database of social care information; (3) quality-assured Internet gateways – OMNI, a searchable catalogue of select evaluated health and medicine internet resources; and (4) Frequency of Inherited Disorders Database (FIDD, Cardiff

University), a repository of data from published literature on the frequency of inherited human disorders worldwide, a first and only such database, but incomplete and has not been updated since 2002 due to funding problems.

The search used terms, MeSH and key words that included: incidence, prevalence, point prevalence, lifetime prevalence of various neurological disorders. All searches were limited to the English language. Authoritative and accredited professional organisational websites were also checked for their publications, including the Association of British Neurologists, the British Neuroscience Association, Neurological Alliance, Neurology-Related Websites and the Frequency of Inherited Disorders Database. The Internet was also scanned through Google as a scoping exercise, using filters to retrieve official NHS, government and academic sources.

Neurological disorders are categorised in this paper into 13 main aetiological and symptom-related groups, including a miscellaneous one of the very rare disorders. They are the infectious, traumatic, headache and migraine, vascular, paroxysmal and convulsive, neuropathies, degenerative, extrapyramidal, genetic, neoplastic, immunological and neuromuscular groups.

Three review articles and a book, which were frequently cited in the literature, in addition to the Frequency of Inherited Disorders Database, were primarily used for this overview [2, 6–9] to extract relevant annual incidence and prevalence rates per 100,000 population. In addition, other sources were identified and it became clear that this information is not complete and methods used to survey patients by various researchers over wide periods of time are not uniform.

Results

Table 1 shows the estimated rates of various neurological disorders and their sources, classed into 13 aetiological groups with the total estimates of each group. In addition to the 5 sources of references already mentioned, others were also found [10–19, 22–27]. The paper by Cockerell et al. [7] was based on surveys carried out in 1966, 1975, 1982, 1986 and 1992, and the same rates were also reported in the Association of British Neurologist report in 1997 [1]. The study by MacDonald et al. [2] was based on an urban population of London covering 13 general practices, with only 80% of their population being white, compared with the UK at 94% in 1994. The article by Kurtzke [6] and the textbook by Batchelor and Cudkovic [8] covered data reported elsewhere. The FIDD on the other hand is an international repository of publications on the frequency of inherited disorders [9]. When the rate of a particular disorder is quoted differently by different sources, value judgement was used in deciding which one to use to calculate the overall estimated accumulated annual incidence and point prevalence rates at the bottom of each system on table 1. These final rates are also used in tables 2 and 3.

Disorder	Rates based on Editorial "[1] Neuroepidemiology in the UK" by O C Cockerell, JWAS Sanders, SD Shorvon. Neuroepidemiology in the UK, J Neurol Neurosurg Psychiatr 1993;56:735-738.	[2] MacDonald BK, Cockerrell OC, Sander JWAS, Sharvov SD. The incidence and lifetime prevalence of neurological disorders in a prospective community-based study in the UK. Brain 2000;123:665-676.	[3] Frequency of Inherited Disorders Database (FIDD)	[4] Kurtzke JF. The current neurologic burden of illness and injury in the USA. Neurol 1982;32:1207-1214.	[5] Batchelor T, Cudkowicz ME. Principles of neuroepidemiology. Ed. 2001, Butterworth- Heinemann Boston, USA.							
	Annual Incidence rate per 100,000	Point prevalence per 100,000	Age & sex adjusted incidence rate /100,000/year	Previously reported incidence rates/100,000/year	Lifetime prevalence/100,000 population	Previously reported point prevalence rates (PP) or estimated prevalence /100,000	Incidence/100,000	Prevalence/100,000	Approximate annual incidence rate per 100,000	Approximate point prevalence rate per 100,000	Annual Incidence rate per 100,000	Prevalence rate per 100,000
1.1 Degenerative Disorders												
Alzheimer's Disease	25,000 in >65^	1,000^									11% of 75+ year olds in Cambridge in 1989	2.3% of 75-79 year olds in Cambridge in 1989
Dementia	40~	40~								50	250	
Motor Neurone Disease	2.4	4.6	2 Brewis 1966, Kurtzke 1984 1-2	10 Kurtzke 1984 4-10 L Hewer 1993 6						2	6	
Dorsolateral sclerosis										3	30	
Annual incidence rate 55/100,000 + 11% of 75+ year olds, which is 11% of 45,500 people, i.e. 5,005 in 2002 Prevalence rate 286/100,000 + 2.3% of 75-79 year olds												
1.2 Extrapyramidal Disorders												
Wilson HLD Parkinson's Disease	12	160	19 Brewis 1966 & Rajput 1984b 12-18	200 PP Kurtzke 1984, Brewis 1966, L Hewer 1993					0.1	20	1	1.6% of those aged 65 and over in Europe
Annual incidence rate 20.1/100,000 Point prevalence rate 201/100,000												
1.3 Paroxysmal and Convulsive Disorders												
Epilepsy	30	2,000	46 24-53#	400#	Pond 1960, RCGP 1960, L Hewer 1993 500			197 ~	50		650 44 person-years in Minnesota USA	680 in 1980 in Rochester Minnesota USA
Febrile fits										50		
Approximate annual incidence rate 96/100,000 Approximate point prevalence rate 650/100,000												

Table 1 (continued)

1.4 Vascular Disorders									
Stroke	200	570	First episode 205£ Second 42£ I.Cranial.H. 10	Bamford 1988 200 Sorensen 1982 Walker 1985 28-35 5% of stroke i.e. 10	900 L. Hewer 1993 500				
Subarachnoid haemorrhage				7 Brewis 1966, Kurtzke 1984 10-15					
Subdural haematoma				6					
Neonatal encephalopathy or stroke				3					
Acute cerebrovascular disease	440~	470~					150	600	
Transient ischaemic attacks							30	150	
Subarachnoid haemorrhage							15	50	
Vascular disease spinal cord							0.5 1 (calculated)		
	Approximate annual incidence rate 412/100,000								
	Approximate point prevalence rate 1,371/100,000								
1.5 Immunological Disorders									
Multiple Sclerosis	5*	110*		7 Brewis 1966, Shepherd &Downie 1980, Kurtzke 1984 2-8	200 Shepherd & Downie 1980, L. Hewer 1993, Rice-Oxley 1995 100		3	60	3.2 Average between 1985- 89 was 95
Other demyelinating diseases							4	12	
	Approximate annual incidence rate 11/100,000								
	Approximate point prevalence rate 122/100,000								
1.6 Neuromuscular Disorders									
Myasthenia gravis	0.22	2.3		3 Aiello 1997 0.25-0.8 Robertson 1998 1	40@		0.4	4	
	Approximate annual incidence rate 3/100,000								
	Approximate point prevalence rate 2,3/100,000								

Table 1 (continued)

1.7 Neoplastic disorders									
Cerebral Tumour malignant	9.3	21	Primary malignant CNS tumour 3	Ryan 1992 5 (F), 6 (M) Kurtzke 1984 5	20	Kurtzke 1984 Primary malignant 5		5.5 (calculated)	5.8 per 100,000 person-years for all races in USA in 1990-1994, 7/100,000 person-years for men vs 4.7/100,000 person-years for women
Cerebral Tumours benign	2.8	28	Primary CNS tumours 10	Brewis 1966 & Walker et al. 1985 7 Counsell 1996 15			10.60 (calculated)	4.6 per 100,000 person-years for all races in USA in 1990-94	
Approximate annual incidence rate 12.1/100,000									
Approximate point prevalence rate 28/100,000									
1.8 Genetic Disorders									
Huntington's Disease		8.4						0.4	5
Friedreich's Ataxia		58							
Charcot-Marie-Tooth peroneal muscular atrophy								0.2 (calculated)	5
Dystonia								2.5	
Tuberous Sclerosis								1.6 in 1988 in Wales	
Duchenne Muscular Dystrophy								10 in 1988 in Wales	
Becker Muscular Dystrophy								2.4 in 1988 in Wales	
Facioscapulo-humeral muscular dystrophy								2 in 1989 in Wales	
Muscular dystrophy, Limb-girdle	1.2	18						1.3 in Scotland in 1979	
Inherited neurological disorders								12.5 in 1988 in Wales	

[illegible][illegible]

Neurological Disorders in Wales

Neuroepidemiology 2007;28:65–78

72

Neuroepidemiology 2007;28:65–78

Table 1 (continued)

Lumbosacral herniated nucleus pulposus											150	300	
Lumbosacral pain syndrome											150		
Cervical herniated nucleus pulposus											15		
	Annual incidence rate of 384/100,000												
	Point prevalence rate 643/100,000												
Grand total of estimated annual incidence rate of neurological disorders in Wales is 2,808.2/100,000 + 11% of 75+ year olds + 1.6/100,000 male births													
Grand total of estimated total prevalence rate is 5,813.6/100,000 + 2.3% of 75-79 year olds													

^ Alzheimer's Society figures based on OPCS estimates 1996. WHO guide to mental and neurological health in primary care. 2003-4 World Health Organisation- UK Collaborating Centre.

" Steiner T J et al. Epidemiology of migraine in England. WHO guide to mental and neurological health in primary care. 2003-4 World Health Organisation- UK Collaborating Centre.

Olesen J, Goadsby PJ. Cluster headache and related conditions. In Olesen J (Ed) Frontiers in Headache Research 1999;9 OUP. WHO guide to mental and neurological health in primary care. 2003-4 World Health Organisation- UK Collaborating Centre.

! Silberstein SD et al. Headache in Primary Care Oxford/Isis Medical Media 1999. WHO guide to mental and neurological health in primary care. 2003-4 World Health Organisation- UK Collaborating Centre.

* Estimated average incidence of MS in South East Wales was 5.41/100,000 for the period 1947-84. The point prevalence was 117/100,000 on 1 January 1985. [Swingler RJ, Compson DA. The prevalence of multiple sclerosis in South East Wales. J Neurol Neurosurg Psychiatr 1988;51:1520-1524].

* The prevalence of MS in South Cambridgeshire was 152/100,000 for all disease classification on 1 July 1993. [Robertson N, Deans J, Fraser M and Compson DAS. Multiple sclerosis in south Cambridgeshire: incidence and prevalence based on district register. J Epidemiol Comm Med 1996;50:274-279.]

* The prevalence of MS was calculated based on the prescribing patterns of 24 GP practices forming the All-Wales General Practice Morbidity Database (GPMDB) in 1996 was 97.9/100,000. [Tremlett HL, Luscombe DK, Wiles CM. Prescribing for multiple sclerosis patients in general practice: a case-control study. J Clin Pharm Ther 2001;26:437-444.]

\$ Annual incidence worldwide of approximately 1.2-8.6 cases per 100,000. [Avila-Funes JA, Mariona-Montero VA, Melano-Carranza E. Guillain-Barre: etiology and pathogenesis. So Revisita De Investigacion Clinica 2002;54:357-363.]

£ The estimated age and sex specific annual incidence rate of first ever strokes in England and Wales in 1999 was 169.8 per 100,000. [Carroll K, Murad S and Eliahoo J. Stroke incidence and risk factors in a population-based prospective cohort study. Health Statistics Quarterly 2001;12:18-25.]

£ The estimated age and sex specific annual incidence rate of recurrent strokes in England and Wales in 1999 was 103.9 per 100,000. [Carroll K, Murad S and Eliahoo J. Stroke incidence and risk factors in a population-based prospective cohort study. Health Statistics Quarterly 2001;12:18-25.]

~ Based on 1999 and 2000 General Practice Morbidity database covering population of around 351,710. GPMDB Annual Report, 2001. Based on fewer practices for Epilepsy rate.

Incidence 40-70 per 100,000 per annum, prevalence 400-800 per 100,000. Figures used by Sign Guideline number 70 on the diagnosis and management of epilepsy.

Table 2. Estimated accumulated annual incidence rates of various groups of neurological disorders

Neurological disorders		Estimated annual incidence rate/100,000
1	Infectious	594
2	Traumatic	553
3	Headache and migraine	450
4	Vascular	412
5	Miscellaneous	384
6	Neuropathies	201
5	Paroxysmal and convulsive disorders	96
7	Degenerative	55 + 11% of 75+ year-olds
9	Extrapyramidal syndromes	20.1
10	Genetic	17 + 1.6/100,000 male births
11	Neoplastic	12.1
12	Immunological	11
13	Neuromuscular (except genetics)	3
Total		2,808.2/100,000 + 11% of 75+ year-olds + 1.6/100,000 male births

Table 3. Estimated accumulated point prevalence rates of various groups of neurological disorders

Neurological disorders		Estimated prevalence rate/100,000
1	Headache and migraine	1,502
2	Vascular	1,371
3	Paroxysmal and convulsive disorders	650
5	Miscellaneous	643
6	Neuropathies	415
4	Traumatic	400
7	Degenerative	286 + Alzheimer's disease at 2.3% of 75- to 79-year-olds (1,047 for the 45,500 people of this age group in Wales in 2002)
8	Extrapyramidal syndromes	201
9	Immunological	122
10	Infectious	98
11	Genetic	95.3
12	Neoplastic	28
13	Neuromuscular (except genetics)	2.3
Total		5,813.6/100,000 + 2.3% of 75- to 79-year-olds

For example, rates quoted by Kurtzke [6] were used for the degenerative system overall rates, as it was the only publication that also covered dorsolateral sclerosis, and for motor neurone disease the figures quoted by all the papers were very close, hence Kurtzke [6] rate was also used and similarly for dementia. Added to that were rates for Alzheimer's disease, which was only quoted by Batchelor and Cudkowicz [8]. Another example is the

incidence rate for epilepsy, which was: 30, 46 and 50; the middle figure 46 was taken when calculating the total rate.

Table 2 shows the estimated accumulated annual incidence rates of neurological disorders grouped by aetiology in a chronological order based on data from table 1. The list is not exhaustive; hence these figures may underestimate the total burden.

Table 4. Estimated number of patients with neurological disorders in Wales in descending order of prevalence

Disorder	Incidence of estimated new cases in Wales based on refs. 7, 20 and reported in ref. 21	Prevalence of estimated total number of cases in Wales based on refs. 7, 20 and reported in ref. 21	Number with significant disability [21]	Estimated number of patients in 1995 taken from national survey of 20 patient organisations that make up the Neurological Alliance [21]	Al-Jader et al. [9] (FIDD)	Estimated number of patients [7]
Epilepsy	2,042	45,513	15,151	21,000		prevalence ~19,842 based on USA, 1980
Stroke	6,419	17,505	10,503			
Alzheimer's disease				21,500		
Head injury	4,668		8,753	4,200 disabled		
Parkinson's disease	525	4,668	3,911	6,250		
Dementia						annual incidence 5,373 point prevalence 2,511 patients
Multiple sclerosis	117	2,917	1,459	4,250		prevalence ~2,772 (1985–89 in USA) annual incidence ~93 cases
Dystonia				1,900	incidence 1:40,000 USA Jews; estimated 73 patients [22]	
Spinal injury	35	1,750	1,751			
Duchenne muscular dystrophy				1,000	prevalence 1:10,000 in 1988 in Wales; estimated 292 patients [10]	annual incidence 35 patients and point prevalence 526 patients
Cerebral tumour	467	1,319	467			
Guillain-Barré syndrome	35	700	140			
Tuberous sclerosis				455	prevalence 1:62,500 in 1988 in Wales; estimated 46 patients [10]	
Huntington's disease		175	175	420	prevalence 1:16,129 or 86 patients in 1994 [23]	
Motor neurone disease	58	175	163	300		prevalence ~117–175 patients
Myasthenia gravis	12	117				annual incidence 6 patients, point prevalence 67 patients
Friedreich's ataxia		58	58		prevalence 1: 322,581 Scotland in 1975; estimated 90 patients [24]	
Charcot-Marie-Tooth peroneal muscular atrophy				60	prevalence 1:6,900 in 1988 in Wales; estimated 423 patients [25]	

Table 4 (continued)

Disorder	Incidence of estimated new cases in Wales based on refs. 7, 20 and reported in ref. 21	Prevalence of estimated total number of cases in Wales based on refs. 7, 20 and reported in ref. 21	Number with significant disability [21]	Estimated number of patients in 1995 taken from national survey of 20 patient organisations that make up the Neurological Alliance [21]	Al-Jader et al. [9] (FIDD)	Estimated number of patients [7]
Progressive supra-nuclear palsy				50		
Becker muscular dystrophy					incidence 1:41,667 in 1988 in Wales; estimated 70 patients [10]	
Facioscapulo-humeral muscular dystrophy					prevalence 1:50,000 or 56 cases in 1989 in Wales [26]	
Muscular dystrophy, limb-girdle					prevalence 1:76,900 in Scotland in 1979; estimated 38 patients [27]	
Inherited neurological disorders					prevalence 1:8,000 in 1988 in Wales; estimated 365 patients [10]	
Neurofibromatosis				60	prevalence 1:7,500 in 1988 in Wales; estimated 389 patients [10]	
Spinal muscular atrophy, distal					prevalence 1:6,000 in 1988 in Wales; estimated 487 patients [10]	
Myotonic dystrophy					incidence 1:14,500 in 1988 in Wales; estimated 201 patients [10]	annual incidence 408 patients, point prevalence 207 patients
Hereditary neuropathy						annual incidence 6 patients, point prevalence 380 patients
Polyneuropathies						~23–79 patients
Very rough estimate of number of patients	14,378	74,897	42,531		2,251 (prevalence and incidence of genetic neurological disorders from FIDD); if we add hereditary neuropathies from Cockerell et al. [7] then total is 2,631	

Table 3 shows the estimated accumulated point prevalence rates of various groups of neurological disorders, which is again not an exhaustive list.

Table 4 shows the estimated number of patients with neurological disorders who live in Wales in a descending order of prevalence. This was based on published incidence and prevalence rates, which were then adjusted using the Office of National Statistics 2002 mid-year estimate of the population of Wales of 2.918 millions. The number of patients with significant disabilities was arrived at from data in tables 1–3 and from various seminal reports and databases [7, 20, 21]. Epilepsy, stroke, Alzheimer's disease, head injury and Parkinson's disease form the most common disorders with the highest number of patients who are left with significant disability.

Discussion

This paper is a pragmatic attempt at summarising the available significant literature on the epidemiology of neurological and neurosurgical disorders. The epidemiology was presented in a format that was useful for the commissioners in Wales, both at an All Wales level for Health Commission Wales and for the Local Health Boards, as they develop their plan for service review.

Unfortunately, authoritative national and international review articles are relatively few and some are 15–23 years old. There are many neurological disorders and some are very rare. There is a dearth of published evidence on the frequency of many of the neurological disorders, especially the very rare.

When compared with other system disorders, most of the long-term neurological conditions have disproportionately higher percentages of physical, sensory, cognitive/behavioural and communication problems. All these problems have an impact on the psycho-social and emotional well-being of these patients.

The infectious or infection-related group of neurological disorders included many conditions that may never come to the attention of a neurologist such as meningitis, shingles and herpes zoster. They usually present to general practice, medical, geriatric or paediatric specialties. Similarly, some of the traumatic cases are usually seen in trauma and orthopaedics specialties. The rest of these disorders are chronic, intermittent and recurrent in nature. They are usually unpredictable such as epilepsy, headache or the early stages of multiple sclerosis.

There are also conditions with sudden onset such as brain and spinal injuries and those conditions that are

progressive in nature such as motor neurone disease, Parkinson's disease or later stages of multiple sclerosis. There are also small groups of conditions that are stable, but with changing needs as the person ages, such as post-polio syndrome or cerebral palsy in the adults.

Table 1 includes a more exhaustive list of disorders reaching an estimated prevalence of grand total of 5,813.6/100,000. Using ONS 2002 mid-year population estimates of Wales, the total was 169,682 patients plus Alzheimer's disease at 2.3% of 75- to 79-year-olds (1,047 patients) making a grand total estimate of 170,729 patients. This translates to 5.8% of the population in Wales having neurological or neurosurgical conditions in 2002. This is more than the prevalence of cancer and diabetes, respectively, both at 5% according to the Welsh Health Survey 2003 and 1998 [National Assembly for Wales: Welsh Health Survey October 2003–March 2004, provisional results, unpublished], although the latter was based on 7,802 self-reporting 16 years and older people. However, patients with headaches, migraines and infectious conditions make a sizeable part of this total figure, and these conditions may not pose the individual resource implications that diabetes and malignant conditions pose.

A rough estimate of the number of patients with some of the main genetic neurological disorders is about 2,781 patients (0.1% or 1:1,049 of the people of Wales and 1.64% of the total load of neurological disorders).

To reflect on the size of the problem for neurology and neurosurgery, which means excluding the infectious group apart from Guillain-Barré, we arrive at a total annual incidence rate of 2,214/100,000 (64,605 patients, 2.2% of the population, table 2).

Although neurosciences have had a relatively low profile particularly when compared with the high political, public and media profile that cancer and cardiac services receive, this overview has strengthened the argument that there is a need to adequately cater for this group of disorders that annually afflict 1:45 of people in Wales.

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