

Neurological disorders in Iraqi refugees in Jordan: data from the United Nations Refugee Assistance Information System

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Abstract The United Nations High Commissioner for Refugees (UNHCR) recognizes 43.7 million forcibly displaced persons and asylum seekers due to conflict and persecution worldwide. Neurological disorders have rarely been described in displaced persons but likely pose a significant burden of disease. We describe the disease spectrum and health service utilization of Iraqi refugees and asylum seekers with neurological disorders using an information system developed by the UNHCR. Neurological

disorders were actively monitored among the 7,642 UNHCR-registered Iraqi refugees and asylum seekers who received health and humanitarian assistance using a pilot, centralized, database called the Refugee Assistance Information System (RAIS) in the Kingdom of Jordan in 2010. There were 122 neurological diagnoses reported in 1,328 refugees (mean age 41 years, 49% female, 10% disabled, 43% with pending resettlement applications) in 2,659 health visits, accounting for 17% of all refugees who sought health assistance in RAIS. Referral to a neurologist occurred in 178 cases (13.4%). The most frequent ICD-10 neurological diagnoses were dorsalgia (back pain) (29.7% of individuals with neurological disorders), headache (13.1%), and epilepsy (12.6%). Approximately 1 in 20 Iraqi refugees with a neurological diagnosis self-reported a history of torture, which was higher than Iraqi refugees without a history of torture [66/1,328 versus 196/6,314, odds ratio (OR) = 1.63, 95% confidence interval (CI) 1.21–2.18]. Neurological disease affects a high proportion of Iraqi refugees, including victims of torture and the disabled. Refugees require dedicated care for treatment of neurological disease with a focus on pain disorders and epilepsy.

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Introduction

The United Nations High Commissioner for Refugees (UNHCR) recognizes more than 27 million refugees, 15 million internally displaced persons, and nearly 1 million people whose asylum applications still need to be adjudicated [1]. There has been limited reporting of neurological disorders among displaced persons. Most data derive from

infectious disease outbreaks, including mortality surveillance of meningococcal meningitis, and disease-specific campaigns involving poliomyelitis and leprosy [2]. Active monitoring of the range of diagnoses, demographic characteristics, vulnerabilities, and health service utilization of refugees with neurological disorders is limited despite the fact that armed conflict, climate change, and economic migration pose important and increasingly global challenges and may have significant effects on the incidence and burden of neurological disease.

In 2011, 8 years after the War in Iraq began, UNHCR reports that there are more than 3.5 million Iraqi persons of concern, including people displaced within or outside of Iraq [3]. Some estimate that 1 in 7 Iraqi civilians have been displaced from their homes [4]. More than 444,000 Iraqi refugees and asylum seekers registered with UNHCR in neighboring countries, including the Syrian Arab Republic, Jordan, Lebanon, Iran, Turkey, Egypt, and the Gulf Cooperation Council countries (1 January 2003 to 31 March 2011). Most Iraqis have fled to the Syrian Arab Republic, Jordan, and Lebanon, even though these countries are not signatories to the 1951 International Convention of Refugees.

The Jordanian Government estimates that between 450,000 and 500,000 Iraqi refugees and asylum seekers live in Jordan [5]. Due to mixed immigration patterns for labor and asylum in the area, others estimate that the total number of Iraqi refugees in Jordan may be around 100,000. A preliminary survey by independent researchers, studying 1,200 households in Jordan in 2007, estimated that 1.7% of Iraqi refugees have a mental disability, with more than 80% of cases attributed to the conflict in Iraq [6]. Neurological disorders accounted for more than a quarter of all cases of mental disability, including developmental problems and memory loss. In neighboring Syrian Arab Republic, 5% of all Iraqi refugees were found to have a neurological problem but further details were not available [7].

Given the limited information on neurological disorders in any refugee setting available to policy-makers, nongovernmental aid organizations, and clinicians, we present data from a large cohort of Iraqi refugees with neurological disorders in Jordan in 2010.

Methods

A web-based system called the Refugee Assistance Information System (RAIS) was launched in Jordan in 2010. RAIS is used to track, monitor, and provide assistance to refugees and asylum seekers (hereafter collectively called “refugees”), including health care, and reports actively collected data from more than 100 centers belonging to 32

organizations in Jordan. This includes UNHCR-affiliated nongovernmental organizations, government-sponsored medical centers, hospitals, primary health care clinics, and pharmacies. Data reported from 1 January through 31 December 2010 were included in this analysis. Each diagnosis entered represents an assessment during an actual health care visit.

Diagnoses were entered into RAIS using the International Disease Classification 10th (ICD-10) edition handbook [8] and made by local health care providers in health centers and hospitals in Jordan. Data entry quality control was achieved through dropdown menus, training and hiring of specialized data entry personnel by nongovernmental organizations and UNHCR, periodic checking of data for accuracy, and cross-referencing with existing databases held by local organizations. Demographic information was verified through the UNHCR by linking with existent registration and document verification systems.

A total of 262 diagnoses deemed to be related to neurological disease were preselected and searched in RAIS in January 2011. For each person with a neurological diagnosis, age, sex, governorate of origin in Iraq, UNHCR-defined specific vulnerability, ICD-10 diagnosis, inpatient versus outpatient evaluation, use of medical procedures, and need for medical referrals were recorded. The relative burden of neurological disease, relationship to specific vulnerabilities, and the frequency of primary neurological diagnoses by number of individuals were calculated. Confidence intervals for odds ratios were obtained by inverting Fisher’s exact test statistic. Although RAIS encompasses persons of any nationality, only persons of Iraqi origin were analyzed here.

The Jordanian government also offers public health assistance to Iraqi refugees at the same price as uninsured Jordanians; health assistance provided to refugees through Jordanian government-run hospitals and clinics paid by public health assistance mechanisms by the Government is not recorded in RAIS. Also, “out-of-pocket” personal expenditures for health care in the private sector by Iraqi refugees who are unregistered with UNHCR are not recorded in RAIS.

Results

At the end of 2010, 31,476 Iraqis in Jordan were registered with UNHCR. A total of 7,642 received health assistance for any diagnosis in Jordan in 2010, forming the source population. There were 1,328 Iraqi refugees with neurological diagnoses (mean age 41 years, median age 41 years, 1st quartile 29 years, 3rd quartile 55 years, range 1–94 years; 50% female), representing 17% of Iraqi refugees who received health assistance from UNHCR (Fig. 1).

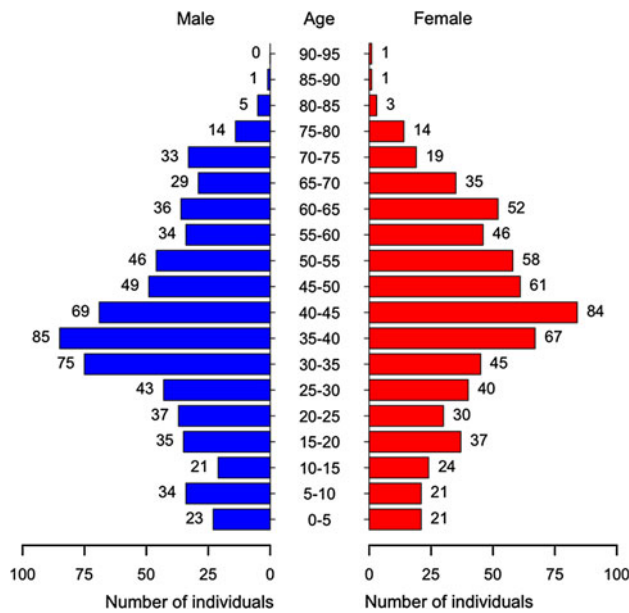


Fig. 1 Population pyramid of the age–sex distribution of Iraqi refugees and asylum seekers with neurological disorders ($n = 1,328$)

These patients were seen in 2,659 health visits (mean 2.00 visits per patient) with 75% in the outpatient setting.

The most frequent neurological diagnoses by number of individuals are shown in Fig. 2. Overall, dorsalgia (back pain) (29.7%), headache (13.1%), and epilepsy (12.6%) were the most common diagnoses among Iraqi refugees with neurological disorders. There were 122 separate diagnoses with at least one case noted. Chronic diagnoses were noted in 71.9% of refugees with neurological disorders. Acute diagnoses were noted in 22.5%. One refugee could have more than one diagnosis throughout the study timeframe. Most common diagnoses by age and specific vulnerability status (UNHCR) are given in Table 1. The most common categories of disease, by number of diagnoses (total 167 diagnoses made), were headache and pain disorders (38.0% of all neurological diagnoses), disorders of the nerve, root, plexus, and muscle (20.7%), epilepsy, vertigo, and related episodic disorders (15.7%), and cerebrovascular diseases (6.0%). Infections, malignancy, and injuries related to the nervous system were rarely reported (Table 2).

Health service needs were studied by type of referral and medical processes or procedures performed. Medical processes/procedures included medical consultation ($n = 2,023$), prescription for medication ($n = 1,530$), referral to a specialist ($n = 658$), physiotherapy ($n = 163$), laboratory investigation ($n = 149$), X-rays ($n = 129$), magnetic resonance imaging ($n = 78$), electromyogram ($n = 58$), electroencephalogram ($n = 41$), computed tomography scan ($n = 36$), glucose level screening ($n = 24$), and other unspecified procedures ($n = 95$). Medical evaluations for

neurological disorders were by practitioners of primary care ($n = 1,164$ cases), neurology ($n = 178$), physiotherapy ($n = 133$), neurosurgery ($n = 154$), orthopedic surgery ($n = 104$), internal medicine ($n = 34$), ear, nose, and throat ($n = 25$), pediatrics ($n = 23$), ophthalmology ($n = 14$), psychology (11), and other specialties ($n = 104$). An individual may have had more than one referral and medical procedure. All evaluations by a neurologist were through referrals by primary care physicians.

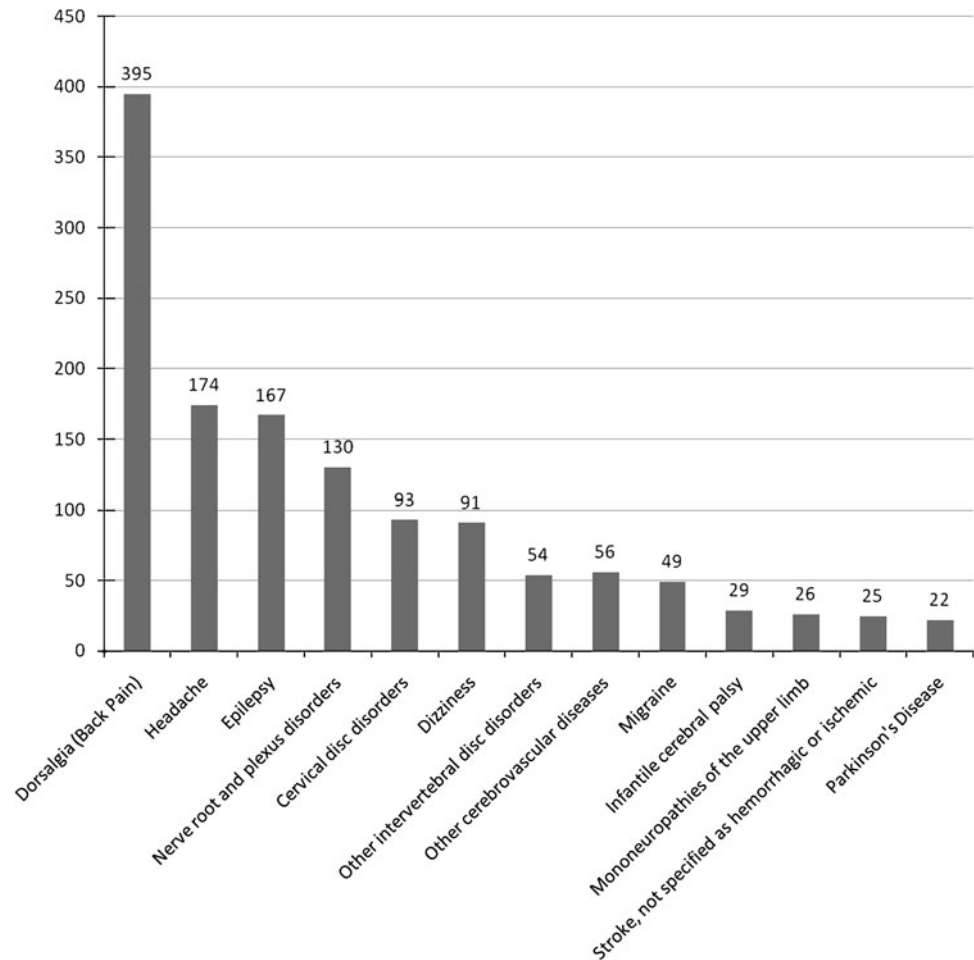
Refugees registered with UNHCR are predominantly from Baghdad (76.5%) and Basrah (4.9%). A slightly lower percentage of those with neurological disorders were found to be from Baghdad (70%), while more were from Basrah (6%). Most (71%) received cash assistance. A total of 31% of the refugees with neurological disorders were deemed to have a serious medical condition, 4% were considered woman at risk, 4% were considered an older person at risk, and 7% had specific legal and protection needs. Ten percent of people with a neurological diagnosis had a disability. Approximately 1 in 20 Iraqi refugees with a neurological diagnosis self-reported a history of torture, which was higher than Iraqi refugees without a history of torture (66/1,328 versus 196/6,314 without neurological diagnoses, OR = 1.63, 95% CI 1.21–2.18).

There were 565 refugees (43%) with neurological disorders who submitted applications for resettlement, including 71 (5%) who departed in 2010. Among individuals with neurological diagnoses who submitted resettlement applications, the most common diagnoses were the same as those who had not applied for resettlement, although the relative frequencies differed slightly: dorsalgia (28% of refugees), epilepsy (15%), and headaches (13%).

Discussion

Iraqi refugees registered with UNHCR experience a significant burden and wide range of neurological disorders that require long-term health services provision, management, and treatment. Much of what has been reported about refugee health is from refugee camps in Asia and sub-Saharan Africa, where infectious disease outbreaks represent a major cause of morbidity and mortality. Iraqi refugees in the Middle East are well educated and scattered throughout cities. This setting differs from other locations where humanitarian aid agencies have customarily provided health assistance [9]. Psychiatric disorders among refugees have been recognized increasingly; however, refugee health needs related to the nervous system are not limited to depression, posttraumatic stress disorder, and anxiety. There is a range of other underlying nervous system disorders that it is imperative to identify, diagnose, and treat.

Fig. 2 Histogram of the most common ICD-10 neurological diagnoses reported in Iraqi refugees by number of individuals



There are limited data on neurological disease in Iraq prior to 2003, including reports on multiple sclerosis [10, 11], stroke [12, 13], neuro-Behçet's disease [14], and epilepsy [15]. Iraqi refugees in this analysis experienced a predominance of pain disorders and epilepsy. These disorders should become priority conditions for the future management of neurological care for refugees in other middle-income settings, particularly in the Middle East and northern Africa as conflict continues in this region. Pain education and treatment, epilepsy drug provision, and stroke risk factor reduction in adults should be considered paramount. A unified, guidelines-based approach for the recognition, control, and minimum standards for treatment of neurological disease has not yet been established in humanitarian aid settings but is a valuable next step for refugee assistance for neurological care.

Certain conditions expected to be common in this population were not commonly seen, most notably traumatic brain injury. It is possible that refugees with certain conditions do not seek humanitarian assistance, do not self-report disease, or have found expedited resettlement in a

third country, or that these disorders are not in fact as common as presumed based on data from combatants in the same region [16]. Civilians with neurological disease may experience stigma in the Middle East, as in many places, leading to reduced care-seeking for neurological problems. Also, it is possible that Iraqis with the most severe neurological conditions and the least amount of resources were unable to leave Iraq. People with specific mental and physical disabilities due to neurological disease may therefore be overrepresented in Iraq and underrepresented in countries of first asylum, although this has yet to be formally studied.

The diseases most commonly seen here include age as a major risk factor, including herpes zoster in the category of neurological infections, spinal disc and root disorders, and stroke. Most conditions seen are amenable to treatment with medications, require follow-up, and would benefit from neurologist-based care. Thirteen percent of refugees with a diagnosed neurological problem had access to a neurologist. Although small, this number likely exceeds the access to care experienced by refugees in most other

Table 1 Selected neurological diagnoses by disease category

Subpopulation (total no. of individuals)	Top three neurological diagnoses (relative frequency of diagnosis in category)
Age 0–5 years (44, 3%)	Epilepsy (27%) Infantile cerebral palsy (14%) Pervasive developmental disorders (9%)
Age 6–18 years (146, 11%)	Epilepsy (36%) Headaches (19%) Infantile cerebral palsy (14%)
Age 19–40 years (448, 34%)	Dorsalgia (35%) Headaches (17%) Epilepsy (11%)
Age 41–65 years (535, 40%)	Dorsalgia (36%) Nerve root and plexus disorders (14%) Headaches (12%)
Age >65 years (155, 12%)	Dorsalgia (21%) Other cerebrovascular disorders (19%) Dizziness & giddiness (12%)
Individuals with a history of torture (66, 5%)	Dorsalgia (38%) Headaches (23%) Cervical disc disorders (14%)
Individuals with a disability (133, 10%)	Epilepsy (20%) Infantile cerebral palsy (17%) Dorsalgia (17%)
Women at risk (52, 8% of women)	Dorsalgia (33%) Cervical disc disorders (17%) Headaches (15%)

settings throughout the world. It is assumed that Iraqi civilians in Iraq have even worse access to neurological and general medical care. Many specialists from tertiary hospitalists are known to have fled Iraq [17].

The UNHCR recognizes that the most durable solution for most Iraqi refugees, especially those with vulnerable status, is third-country resettlement. Presently, most Iraqi refugees who resettle go to the USA [18]. In third countries of residence everywhere, including Canada, the UK, Sweden, Norway, France, and others, the long-term health needs of refugees will be of high importance. The recent development of electronic databases for health surveillance in refugees has led to a potentially new monitoring approach for chronic and treatable neurological disorders. This system can identify not only basic demographic information including age–sex profiles, but ultimately, may also be used to recognize important risk factors, access to treatment, medication availability, uptake of services, and

the effects of treatment on amelioration of symptoms. If clinical data are promptly reported, this would allow “real-time” monitoring of trends in neurological disease in this population, particularly as migration patterns change.

This study was limited by dependence on nonneurologist physicians and other health care workers to recognize, diagnose, and report neurological problems. No information is available on whether these disorders were new following the invasion of Iraq, related to conflict or exposures during the war, or existed prior to armed conflict. Importantly, refugees who seek private health care may have a different disease profile than refugees registered with UNHCR, and are not captured in this database. It is assumed that refugees registered with UNHCR are sicker than refugees who have not registered for assistance, but this assumption has not been studied. A field study of 1,200 households [6] found that 77% of all Iraqi households in Jordan were registered with UNHCR. The use of diagnostic testing in this subpopulation is not high in comparison with high-income countries. It is also unclear how many people with a given diagnosis receive adequate treatment, such as control of seizures and access to antiepileptic drugs. The reporting of neurological and all disorders in RAIS is best considered health care utilization and not health care needs, the latter of which are likely higher. This is not an epidemiological study of disease prevalence, since Iraqi refugees who do not seek care or who pay out of pocket for private health care or receive public health services from the Jordanian Government exclusively will remain uncounted.

More research will be required to understand how, why, and when refugees seek care for neurological diagnoses. We hope reporting this data will stimulate future work on neurological disorders in refugees. In the meantime, this preliminary understanding of neurological disorders in vulnerable displaced persons is crucial to developing sustainable policy measures to recognize and ultimately address what may be a large and lifelong burden of neurological disorders in refugee populations. Refugee populations continue to grow worldwide as civilians increasingly and often inadvertently become part of modern armed conflict. Conflict today often involves areas where neurological care is already available but where infrastructure and personnel can be easily overwhelmed when high numbers of refugees arrive.

In the longer term, the incidence of neurological disorders such as brain tumors and congenital malformations is also worthy of investigation in times of armed conflict because of potential toxic exposure to teratogens or carcinogens during the war. This propensity to develop neurological disease that does not manifest acutely but may affect refugees throughout a lifespan has not yet been estimated.

Table 2 Selected neurological diagnoses in Iraqi refugees by disease category

Burden of most frequent neurological disorders by category	No. of individual cases with that diagnosis ^a
Neurological infectious disorders	<i>n</i> = 26
Meningitis (bacterial, viral, tuberculous, parasitic, and other infectious)	7
Leprosy	2
Intracranial and intraspinal abscess and granuloma	2
Meningococcal infection	1
Other viral infections of the CNS not elsewhere classified	1
Herpes zoster	13
Dementia and cognitive disorders	<i>n</i> = 22
Alzheimer's disease/dementia in Alzheimer's disease	8
Dementia in other diseases classified elsewhere	8
Other degenerative disorders of the nervous system, not elsewhere classified	1
Personality and behavioral disorders due to brain disease, damage, and dysfunction	1
Other symptoms and signs involving cognitive functions and awareness	1
Unspecified dementia	3
Disorders of the nerve, root, plexus, and muscle	<i>n</i> = 347
Cranial nerve disorders in diseases classified elsewhere	1
Cervical disc disorders	93
Nerve root and plexus disorders	130
Mononeuropathies of the upper limb	26
Mononeuropathies in diseases classified elsewhere	2
Guillain–Barré syndrome	1
Hereditary and idiopathic neuropathy	1
Myasthenia gravis and other myoneural disorders	1
Nerve root and plexus compressions in diseases classified elsewhere	6
Disorders of myoneural junction and muscle in diseases classified elsewhere	1
Disorders of autonomic nervous system	3
Disorders of muscle not elsewhere classified	1
Neuromuscular dysfunction of bladder, not elsewhere classified	1
Myositis	3
Primary disorders of muscles	1
Other myopathies	2
Other disorders of muscle	19
Other polyneuropathies	1
Other mononeuropathies	1
Other intervertebral disc disorders	54

Table 2 continued

Burden of most frequent neurological disorders by category	No. of individual cases with that diagnosis ^a
Congenital and neurodevelopmental disorders	<i>n</i> = 82
Birth injury to the peripheral nervous system	1
Down's syndrome	2
Infantile cerebral palsy	29
Spina bifida	3
Specific developmental disorders of speech and language	7
Specific developmental disorders of scholastic skills	2
Mild mental retardation	4
Moderate mental retardation	1
Severe mental retardation	2
Unspecified mental retardation	1
Other mental retardation	3
Other mental disorders due to brain damage and dysfunction and to physical disease	15
Other disturbances of cerebral status of the newborn	1
Microcephaly	3
Anencephaly	1
Other congenital malformations of the brain	1
Pervasive developmental disorders	4
Other disorders of psychological development	1
Tic disorders	1
Headache & pain disorders	<i>n</i> = 644
Dorsalgia (back pain)	395
Headache	174
Migraine	49
Other headache syndromes	7
Other dorsopathies, not elsewhere classified	3
Disorders of trigeminal nerve	1
Pain, not elsewhere classified	15
Episodic disorders	<i>n</i> = 262
Epilepsy	167
Convulsions, not otherwise classified	1
Eclampsia	2
Dizziness and giddiness	91
Vertiginous syndromes in diseases classified elsewhere	1
Cerebrovascular diseases	<i>n</i> = 101
Intracerebral hemorrhage	2
Subarachnoid hemorrhage	2
Stroke, not specified as hemorrhage or infarction	25
Other cerebrovascular diseases	56
Transient ischemic attacks and related symptoms	10

Table 2 continued

Burden of most frequent neurological disorders by category	No. of individual cases with that diagnosis ^a
Cerebrovascular disorders, not elsewhere classified	4
Sequelae of cerebrovascular disease	2
Injuries	<i>n</i> = 46
Injury of nerves and spinal cord at thorax level	2
Injury of nerves at ankle and foot level	1
Injury of nerves at shoulder and upper arm level	4
Injury of nerves at wrist and hand level	2
Injury of nerves at neck level	1
Fall on and from stairs and steps	7
Crushing injury of head	1
Fracture of skull and facial bones	5
Unspecified fall	5
Superficial injury of head	4
Other and unspecified injuries of the head	6
Intracranial injury	1
Dislocations, sprains, and strains of joints and ligaments of the head	1
Sequelae of injuries of neck or trunk	1
Sequelae of injuries of head	1
Toxic effects of contact with venomous animals	4
Movement disorders	<i>n</i> = 49
Abnormal involuntary movements	16
Huntington's disease	3
Other extrapyramidal and movement disorders	1
Abnormalities of gait and mobility	3
Parkinson's disease	22
Parkinsonism in diseases classified elsewhere	1
Secondary parkinsonism	1
Dystonia	1
Other lack of coordination	1
Neoplasms	<i>n</i> = 19
Benign neoplasm of the brain and other parts of the CNS	3
Malignant neoplasm of brain	15
Neoplasm of uncertain or unknown behavior in brain and central nervous system	1
Other	<i>n</i> = 79
Facial nerve disorders	13
Cranial nerve disorders in diseases classified elsewhere	2
Speech disturbances, not elsewhere classified	2
Multiple sclerosis	13
Other demyelinating diseases of CNS	1
Encephalitis, myelitis, encephalomyelitis in diseases classified elsewhere	1
Congenital hydrocephalus	1
Hydrocephalus	2

Table 2 continued

Burden of most frequent neurological disorders by category	No. of individual cases with that diagnosis ^a
Dysphagia	4
Hemiplegia	3
Paraplegia and tetraplegia	8
Somnolence, stupor, and coma	6
Sleep disorders	1
Conductive and sensorineural hearing loss	7
Mental and behavioral disorders due to use of alcohol	3
Neuromuscular dysfunction of bladder, not elsewhere classified	1
Other paralytic syndromes	2
Other disorders of brain	3
Other disorders of brain in diseases classified elsewhere	2
Other disorders of nervous system in diseases classified elsewhere	2
Other diseases of spinal cord	1
Spinal muscular atrophy and related syndromes	1

^a A single individual may have more than one neurological diagnosis
CMS central nervous system

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Conflict of interest All authors declare no disclosures and no competing interests.

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