

## Section Editors

Johan A. Aarli, MD  
Oded Abramsky, MD,  
PhD, FRCP

# Reportable neurologic diseases in refugee camps in 19 countries



Farrah J. Mateen, MD  
Marco Carone, PhD  
Christopher Haskew, MD  
Paul Spiegel, MD, MPH

Correspondence & reprint  
requests to Dr. Mateen:  
Fmateen@jhsp.edu

## ABSTRACT

**Background:** Approximately one-third of refugees worldwide live in refugee camps. Selected neurologic diseases are actively reported in some refugee camps.

**Methods:** The United Nations High Commissioner for Refugees monitors health visits in refugee camps with the assistance of more than 25 partner organizations using standardized case definitions. Neurologic diseases were selected and searched for the years 2008 to 2011. The number of health care visits for a neurologic disease was calculated and divided by the aggregated number of reporting months available for each refugee camp (“visits per camp-month”).

**Results:** Five neurologic diseases were reported from 127 refugee camps in 19 countries. Visits for chronic, noncommunicable diseases including epilepsy (53,941 visits in 1,426 camp-months, 48% female) and cerebrovascular disease (4,028 visits in 1,333 camp-months, 51% female) far exceeded those for neurologic infectious diseases (acute flaccid paralysis/poliomyelitis, 78 visits in 3,816 camp-months, 42% female; leprosy, 74 visits in 3,816 camp-months, 66% female; meningitis, 477 visits in 3,816 camp-months, 51% female). In 2011, these diseases accounted for 31,349 visits globally with 91% of visits for epilepsy.

**Conclusions:** Targeted programs addressing epilepsy and stroke among refugees in camps should become a priority and indicate that other chronic neurologic diseases that may be under- or misdiagnosed may also be common in refugee camps. Given that significant under-reporting is likely, our findings demonstrate the pressing need for coordinated preventive and interventional measures for epilepsy and stroke in refugee camps. *Neurology*® 2012;79:937-940

## GLOSSARY

**UNHCR** = United Nations High Commissioner for Refugees; **webHIS** = Web-based Health Information System.

Approximately 30% of refugees lived in refugee camps in 2010, including 52% of children and 49% of women.<sup>1</sup> Refugee camps are meant to be temporary locations for shelter and emergency aid provision, usually established by governments or international agencies in response to natural disaster, famine, political discord, or armed conflict. Although not recognized as a durable solution, refugee camps may be the home of entire generations of refugees and reach populations of more than 100,000 people per camp.<sup>1</sup>

Limited information is available on neurologic diseases in refugee camps, and is mainly focused on meningococcal meningitis outbreaks during the 1990s.<sup>2-5</sup> Compiled surveillance data would be valuable for setting health care policy related to the prevention, management, and reduction of neurologic diseases in refugee camps on a global basis. Here, we present the burden of health care visits per reportable neurologic disease by country level from refugee camps supported by the United Nations High Commissioner for Refugees (UNHCR).

**METHODS Data reporting and collection.** The UNHCR Web-based Health Information System (webHIS) is a standardized reporting tool designed to monitor the health status of refugees and other persons of concern to the UNHCR. Selected reportable diseases are monitored when they have the potential to affect refugees in high numbers or lead to important interventions. Data are

## Podcast



From the Department of Neurology (F.J.M.), the Johns Hopkins Hospital, Baltimore; Department of International Health (F.J.M.), the Bloomberg School of Public Health, Baltimore, MD; Division of Biostatistics (M.C.), School of Public Health, University of California, Berkeley; and United Nations High Commissioner for Refugees (C.H., P.S.), Geneva, Switzerland.

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**Table 1** Overview of reportable neurologic disease visits to the UNHCR (2008–2011)

Disease	No. of cases reported	No. of camp-months reported	Counts per 1,000 reporting camp months	% Female
Acute flaccid paralysis (acute flaccid paralysis in a child aged <15 years, including Guillain-Barré syndrome or any paralytic illness in a person of any age or a person of any age in whom the clinician suspects polio)	78	3,816	20.4	42
Cerebrovascular disease (disease of the blood vessels and, especially, the arteries that supply the brain: International Classification of Disease 160–169: Cerebrovascular diseases, including stroke)	4,028	1,333	3,021.8	51
Epilepsy (a person with epilepsy has at least 2 episodes of seizures not provoked by any apparent cause such as fever, infection, injury, or alcohol withdrawal; these episodes are characterized by loss of consciousness with shaking of the limbs and sometimes associated with physical injuries, bowel/bladder incontinence, and tongue biting)	53,941	1,426	37,826.8	48
Leprosy (no case definition provided)	74	3,816	19.4	66
Meningitis (any person with sudden onset fever, >38.0°C axillary or >38.5°C rectal, and one of the following signs: neck stiffness, altered consciousness, other meningeal sign, or petechial/purpurial rash; in patients under 1 year, meningitis is suspected when fever is accompanied with bulging of a fontanelle)	477	3,816	125	51
<b>Total</b>	<b>58,598</b>	<b>—</b>	<b>—</b>	<b>48</b>

Abbreviation: UNHCR = United Nations High Commissioner for Refugees.

collected at each camp by UNHCR employees and other aid workers on a weekly basis, involving 25 implementing organizations worldwide, using case definitions (table 1). Approximately 1.6 million displaced persons are covered by camps participating in the webHIS. Visit data are collected via a standardized online reporting form, downloaded at the refugee camp site, and deposited electronically each month. Not all refugee camps report on all reportable neurologic diseases every month. For each month, the number of camps reporting on the disease of interest was calculated. The tallies were then summed over months and used to standardize the reporting counts of specific diseases, yielding per camp-month visit rates. This standardization allowed counts to be compared across various strata (e.g., sex, reporting years).

For each health visit, patient sex, location, and month of encounter were reported. Neurologic diseases were searched among all reportable diseases in webHIS during the study time-frame (January 1, 2008–December 31, 2011 for acute flaccid paralysis, leprosy, and meningitis; July 1, 2009–December 31, 2011 for cerebrovascular disease and epilepsy). Camp level information is available at <https://unhcr.org/his>. Use of deidentified programmatic data used in this study was approved by The Johns Hopkins University Institutional Review Board.

**RESULTS** Participating countries were from 3 World Health Organization–defined regions: African (93 refugee camps in 13 countries: Burundi, Cameroon, Central African Republic, Chad, Democratic Republic of Congo, Ethiopia, Guinea, Kenya, Namibia, Rwanda, Tanzania, Uganda, Zambia), Eastern Mediterranean (14 refugee camps in 3 countries: Djibouti, Sudan, Yemen), and Southeast Asian (20 camps in 3 countries: Bangladesh, Nepal, Thailand). The countries with the highest number of reporting camps were Chad (n = 28), Ethiopia (n = 13), Uganda (n = 11), Sudan (n = 10), and

Cameroon (n = 10). Reporting of epilepsy and cerebrovascular disease began in July 2009 and was available in 14 countries for cerebrovascular diseases and 16 countries for epilepsy (table 2).

There were 5 reported neurologic diseases in the webHIS of the UNHCR. In 2011, these diseases accounted for 31,349 visits globally of which 91% were for epilepsy. The age distribution of the 53,941 health visits for epilepsy for all years reported was as follows: <5 years old (n = 3,964 visits, 7.3%), 5–17 years old (n = 22,736 visits, 42.1%), 18–59 years old (n = 22,489 visits, 41.7%), and >60 years old (n = 719 visits, 1.3%). Age information was unavailable for 4,038 visits (7.5%). Table 1 compares the reported health visit utilization of neurologic disease, standardized by number of reporting months available.

**DISCUSSION** The UNHCR webHIS demonstrates feasibility of an active reporting system for key neurologic diseases in refugee camps on a global basis. WebHIS depends on the skills of nonphysician health care workers to report on neurologic diseases to monitor disease outbreaks, reveal health utilization trends, and develop broad estimates of the burden of disease. To date, most reported neurologic diseases of interest to UNHCR have been infectious in nature. However, these results suggest that infectious neurologic diseases are much less common than epilepsy and stroke.

The recent inclusion of stroke and epilepsy on reporting forms will be crucial for future humanitar-

**Table 2** Location and burden of neurologic disease visits by country for refugee camps reporting to UNHCR webHIS (2008–2011)

Country (no. of refugee camps)	Names of reporting refugee camps	No. of health visits for cerebrovascular disease per 1,000 camp-months	No. of health visits for epilepsy per 1,000 camp-months	No. of health visits for acute flaccid paralysis per 1,000 camp-months	No. of health visits for leprosy per 1,000 camp-months	No. of health visits for meningitis per 1,000 camp-months
<b>African region</b>						
Burundi (n = 4)	Bwagiriza, Gasorwe, Gihinga, Musasa	370	14,426	24	0	8
Cameroon (n = 10)	Batouri, Bertoua, Betare-oya, Djohong, Garoua Boulai, Kette, Langui, Meiganga, Ndelele, Tibati	Not reported	Not reported	19	0	142
Central African Republic (n = 3)	Batalimo, Pladama, Zemio	Not reported	154	0	0	48
Democratic Republic of Congo (n = 3)	Birambizo, Goma, Masisi	Not reported	481	214	0	2,286
Chad (n = 28)	Amboko, Amnabak, Aradib, Betimera, Bredjing, Daha, Djabal, Dosseye, Farchana, Gaga, Gassire, Gondje, Gouroukoune, Goz Amer, Habile, Iridimi, Koloma, Koubigou, Kounaunga, Koy, Massambagne, Mile, Moula, Moyo, Oure Cassoni, Touloum, Trejuine, Yarougou	636	11,351	20	24	311
Ethiopia (n = 13)	Awbarre, Bokolmanyo, Bonga, Dimma, Fugnido, Hilaweyn, Kebribeyah, Kobe, Mai Aini, Melkadida, Sheder, Sherkole, Shimelba	356	11,628	23	39	29
Guinea (n = 1)	Kouankan II	Not reported	Not reported	0	0	25
Kenya (n = 6)	Dagahaley, Hagadera, Ifo, Ifo 2, Kakuma, Kambioos	8,535	85,929	35	5	141
Namibia (n = 1)	Osire	1,316	7,800	0	0	0
Rwanda (n = 3)	Gihembe, Kiziba, Nyabiheke	Not reported	26,275	0	0	18
Tanzania (n = 6)	Lugufu, Lukole, Mtabila, Mtabila II, Nduta, Nyarugusu	Not reported	376,708	15	119	15
Uganda (n = 11)	Adjumani, Imvepi, Kiryandongo, Kyaka II, Kyangwali, Madi Okollo, Nakivale, Oruchinga, Palorinya, Rhino Camp	629	18,153	39	21	174
Zambia (n = 4)	Kala, Maheba, Mayukwayukwa, Mwange	3,083	1,155	7	88	29
<b>Eastern Mediterranean</b>						
Djibouti (n = 1)	Ali Adde	276	31,345	0	0	0
Sudan (n = 10)	Abuda, Fau 5, Girba, Kilo 26, Lasu, Lologo, Shagarab I, Shagarab II, Shagarab III, Suki, Um Gargour, Wad Sharifey	Not reported	Not reported	43	0	0
Yemen (n = 3)	Basateen, Kharaz, Sanaa	4,557	12,875	8	0	24
<b>Southeast Asian</b>						
Bangladesh (n = 3)	Kutupalong, Leda site, Nayapara	1,026	711	0	0	18
Nepal (n = 8)	Beldangi, Beldangi I, Beldangi II, Beldangi II ext, Goldhap, Khudunabari, Sanishare, Timai	4,176	53,808	3	3	0
Thailand (n = 9)	Ban Don Yang, Ban Mae Surin, Ban Mai Nai Soi, Mae La, Mae La Oon, Mae Ra Ha Luang, Nu Poh, Tham Hin, Umpiem Mai	4,170	20,204	2	9	56

Abbreviations: UNHCR = United Nations High Commissioner for Refugees; webHIS = Web-based Health Information System.

ian crises. Epilepsy represents more than 9 out of every 10 visits for reportable neurologic diseases in refugee camps. The underlying causes of epilepsy and seizures in refugee camps are unknown, but likely represent similar risk factors to other inhabitants in the same region, including perinatal injury and birth

defects, febrile seizures, head trauma, genetic diseases, cerebral malaria, previous stroke, and related causes. The overall aging population and existence of affordable medications on the WHO Essential List of Medicines should lead to more precise and field-tested case definitions for neurologic diseases among

refugees in camps, including studies focusing on different age groups. It is not reported whether cases were treated or untreated. If, however, each health visit for epilepsy represented one individual who required antiepileptic drug treatment, the cost of phenobarbital to treat all refugees would be relatively small. Given a median defined daily dose of phenobarbital of 100 mg, the cost to treat all refugees with epilepsy in camps would be approximately \$270,000 USD (estimated approximately \$5 USD per person per year).

Monitoring of meningitis in sub-Saharan Africa is an important way to avoid epidemic outbreaks due to *Neisseria meningitidis*. Although likely underreported here, the overall low counts of meningitis should be considered as a success of surveillance, treatment, and recent vaccination campaigns. In Goma, Democratic Republic of Congo (former Zaire) in 1994, recovery rates from meningococcal meningitis treated with IV penicillin and chloramphenicol in a field hospital were comparable to rates found in advanced medical facilities.<sup>2</sup> Early vaccination against meningococcal meningitis in a refugee camp of Sudanese nationals in northern Uganda led to less deaths compared to a camp where vaccination was delayed.<sup>3</sup> Simple, reliable surveillance systems for meningitis have been advocated for more than 20 years<sup>4</sup>; however, even when implemented, important infectious disease outbreaks can be missed. The eventual inclusion of dementia, traumatic head and spinal cord injury, cerebral palsy, and chronic pain will also be important in the surveillance of neurologic diseases in future humanitarian crisis settings; this will require further training of medical staff on diagnosis and treatment.

We recognize important limitations to reporting data from the webHIS. Data are reported for each visit rather than for each refugee. The population structure of refugee camps is not static. Therefore, incidence and prevalence estimates of disease by country and camp level cannot be made. Data were entered based on standard case definitions and were not verified by physicians in many cases. Cases of meningitis were unlikely to have had routine CSF confirmation, and others may not have reached medical attention. Cerebral malaria and multiple other

neurologic diseases of importance to refugees may not be reported because of a lack of training and limited monitoring of implementation of individual reporting categories. Therefore, it is assumed that there is significant under-reporting and risk of misclassification of most neurologic diseases.

However, given the available evidence, there is a growing need for guidelines for the prevention, evaluation, and care of refugees with neurologic diseases. This includes better coordination of information and action through roll-out programs for aspirin, antihypertensive medications, phenobarbital, phenytoin, analgesics, and potentially other antiepileptic drugs and levodopa. Since refugee camps often have better reporting capacity and treatment availability than for populations in the host country, attention to the neurologic health of refugees can advance care in the larger geographic regions where camps exist.

### AUTHOR CONTRIBUTIONS

Dr. Mateen was involved with data interpretation, data analysis, writing, and editing of the manuscript. Dr. Carone was involved with data interpretation, data analysis, writing, and editing of the manuscript. Dr. Haskeew was involved with data acquisition, data interpretation, and editing of the manuscript. Dr. Spiegel was involved with data acquisition, data interpretation, and editing of the manuscript.

### DISCLOSURE

The authors report no disclosures relevant to the manuscript. **Go to [Neurology.org](http://www.neurology.org) for full disclosures.**

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