



## Meeting the neurological needs of refugees and other forcibly displaced people

Awareness of the particular neurological problems that can affect refugees and internally displaced people can expedite diagnosis, and cultural sensitivity and empathy can expedite treatment. But where are the guidelines to help? Adrian Burton investigates.



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**Refugees on the Afghanistan–Pakistan border**

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For more on **refugee numbers** see <https://www.unhcr.org/figures-at-a-glance.html>

For more on the **distribution of refugees** see <https://www.weforum.org/agenda/2017/06/eighty-four-percent-of-refugees-live-in-developing-countries/>

For more on **neurological disease in refugee camps** see *Neurology* 2012; **79**: 937–40

For more on **neurological, mental, and substance use problems in refugee camps** see *BMC Med* 2014; **12**: 228

For more on **neurological emergencies in refugees in Germany** see *Front Neurol* 2018; **9**: 1088

For more on **sex differences in neurological problems in Yazidi refugees** see *Eur J Psychotraumatol* 2016; **7**: 28556

For more on **brain functional connectivity in refugees** see *Psychol Med* 2019; **12**: 1–8

For more on the **case report of difficulties of care faced by a refugee** see *Surg Neurol Int* 2015; **6**: 168

For more on the **neurological profiles of Syrian asylum-seekers** see *Eur Neurol* 2018; **80**: 249–53

According to the UN High Commission for Refugees, 68.5 million people have been forcibly displaced from their homes by conflict or persecution. Some 40 million are internally displaced and 25.4 million are refugees; 3.1 million asylum seekers make up the remainder. Although some might find new homes in high-income countries, about 84% have sought refuge in low-income and middle-income countries. Turkey is currently home to the largest number of refugees globally (more than 3.5 million); Uganda, Pakistan, Lebanon, Jordan, Iran, and occupied Palestinian territory are hosts to many of the rest. However, physicians everywhere are now increasingly likely to have to treat forcibly displaced people. Providing the best care for them could depend on doctors' awareness of the particular neurological problems that certain groups might face and on their understanding of how a patient's history, culture, and beliefs might influence the success of treatment. It's a lot to ask, however, for medical professionals—whether working in well-equipped clinics or camps for internally displaced people—to be aware of every neurological condition that might affect every population, or to be conversant with every culture they encounter. Specific guidelines would be helpful and voices calling for them are starting to be raised.

Certainly, neurologists and other health workers who care for forcibly displaced populations face a range of challenges in establishing diagnoses and delivering treatment. The palette of diseases and disease burdens in such populations might differ from what clinicians are used to and might even depend on the setting in which

patients are seen. For example, a study of 127 refugee camps across Africa and Asia found that epilepsy accounted for up to 91% of all neurological visits (37 867 per 1000 reporting camp months) from five reportable diseases including epilepsy, acute flaccid paralysis, cerebrovascular disease, leprosy, and meningitis. The second most common cause of neurological visits was cerebrovascular disease. A similar study involving refugee camps in African and Asian countries also found epilepsy to be the most common reason for a visit among neurological, mental, and substance-abuse problems. However, in most Syrian, Iraqi, and Afghan refugees seeking assistance for neurological emergencies in Germany, the most common diagnosis was a non-epileptic seizure or a psychiatric disorder (27% compared with 15% for native Germans), whereas a diagnosis of stroke was rare. There are also sex differences to consider. For example, in Iraqi Yazidi refugees in Turkey, women were found more likely to have post-traumatic stress disorder and major depression than men. Further, although neurologists might understand the stress-induced tension headaches with which refugees often present, they might not be so familiar with the pain caused by war trauma or torture, neuropsychiatric problems, such as difficulties with processing emotions caused by heightened frontal-amygdala connectivity, or diseases they have only seen in textbooks. Certainly, Behcet's disease, Chagas disease, or brain parasite-induced epilepsy might not immediately be suspected by neurologists in some host countries.

Health-care workers might also need to contend with not having medical

records for these patients, and with language and cultural barriers that can hinder an accurate diagnosis and the delivery and monitoring of treatment. Some of these problems might be reflected in the mean delay time to diagnosis in the aforementioned Syrian, Iraqi, and Afghan refugees, which was found to be twice that for German patients (220 vs 123 min). A case report from Canada highlights how all these problems, plus mistrust of new nursing staff when shifts changed, as well as unfamiliar perspectives regarding treatment, negatively affected the care of a female refugee patient who required neurosurgery. Moreover, there is always the danger of never seeing the patient again. A Turkish study reported that 96% of Syrian asylum seekers did not attend follow-up appointments for neurological conditions, a problem the authors suggest might be linked to socioeconomic conditions, despite Turkey providing refugees with free medical coverage.

However, no specific guidelines yet exist to help health workers identify and meet the neurological needs of any forcibly displaced population, neither in humanitarian emergencies nor in their aftermath. Aware of this deficit, Farrah Mateen (Associate Professor of Neurology, Harvard University, Boston, MA, USA) has made a call for guidelines on minimum standards of care to be devised. "To realistically meet the neurological needs of displaced populations, whatever their formal political status, we require considerable work on their baseline epidemiology", she insists. "Refugee health deserves an evidence base. Most of the available literature is outdated, focused on tropical regions, or reports on the

health of combatants rather than civilians.” Indeed, basic vaccination needs have been prioritised and surveillance work for poliomyelitis, meningitis, and leprosy have largely been the focus of international efforts, when epilepsy and perhaps stroke clearly affect many more people. “What is occurring today is something far more expansive, complex, and costly”, continues Mateen. “There need to be guidelines for neurological care, but [in many places] one cannot depend on a neurologist being the provider, so we need to think creatively.”

The likelihood that non-neurologists will often be those charged with delivering neurological care is made clear by the situation in east Africa. “There is no dedicated neurology service catering to displaced persons in the Uganda/Kenya region”, says Augustina Charway-Felli, Secretary-General and President Elect of the African Academy of Neurology (AFAN; Accra, Ghana), “and hence there are no formal guidelines for the care of those with neurological disease. To put this into context, there are about ten or fewer neurologists in either of these countries. In the best-case scenario, this means that most patients would likely be seen by a non-specialist medical officer or physician assistant/clinical officer. Some people may be seen for neurological problems in city hospitals, but no data exist on such encounters. Indeed, there is generally very little information on the spectrum of neurological disease that refugees contend with. Guidelines would definitely be of use, but they would require some tailoring to suit the locale and availability of medications and medical access, etc.”

Data are being collected in Turkey—where again, the authorities caring for refugees’ neurological health have no special guidelines to help them—that makes the importance of such tailoring very clear. “Some 34% of refugees in Turkey have a stress-related condition because their family members have been killed or were injured during the war in Syria; sleeping disorders are seen

in 20%, especially among those living in camps; and headache is reported by around 15%”, says Şerefür Öztürk, President of the Turkish Neurological Society (Selçuk University Faculty of Medicine, Konya, Turkey). “Fruit, vegetable, and salt consumption are different to those of the Turkish population; 60% of Syrian refugees have never had their blood pressure measured—indeed, 56% of those now in Turkey have been diagnosed with high blood pressure—and 80% have never had their blood sugar measured. Any strategy for treating or reducing the risk of refugees developing chronic neurological disorders needs to take these things into account.”

“There is no one-size-fits-all solution here”, insists Paul Spiegel (Director of the Center for Humanitarian Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA). “An improved understanding of the epidemiology, disease presentation and cultural beliefs about neurological diseases by persons displaced by conflict is needed for neurologists and other health professionals to better prevent problems and treat refugee patients. Guidelines according to different regions of the world will be needed to help health-care workers, from community-based workers through to neurologists.”

Getting together the different sets of guidelines needed would, however, be an enormous task requiring input not just from neurologists, but from epidemiologists, linguists, anthropologists, medical workers on the ground, non-government organisations, national and international neurological societies, the UN High Commission for Refugees...And where to start? “I believe we need to focus on the poorest and most vulnerable groups first and establish minimum goals within a human rights approach”, says Mateen. “Guidelines could lead to meaningful change if there is stakeholder buy-in beyond neurologists.”

Neurologists, at least, are now beginning to express an interest in buying

in. “The global plight of refugees and internally displaced persons has raised awareness of the unique and complex health needs of these disadvantaged populations”, says Ralph Sacco, President of the American Academy of Neurology (University of Miami, Miami, FL, USA). “The American Academy of Neurology’s International Subcommittee will be discussing the possibility of collaborating with the American Neurological Association, the European Academy of Neurology (EAN), the World Federation of Neurology, and the World Health Organization to gather information and develop educational materials for neurologists and non-neurologists involved in the care of refugees with neurologic problems.”

“The EAN agrees with the need for awareness and education regarding the neurologic care of refugees and is now planning to discuss this at the 2019 EAN Annual Congress [June 29–July 2, Oslo, Norway]”, confirms EAN President Franz Fazekas (University of Graz, Graz, Austria). “We will exchange information on these issues with representatives of the European National Neurologic Societies and team up with fellow Academies and the World Federation of Neurology to address the problems.”

“I personally and on behalf of AFAN, think that it makes sense that these guidelines are created in collaboration with each other as we, from our different perspectives, will be able to create [material] that will be applicable to the interest group, based on what is available to [local health-care providers]. I am confident that these issues will be raised during the Africa task force business meeting amongst others at the Oslo congress”, says Charway-Felli.

When will they be ready? That is hard to say, although things are starting to move. How ironic, though, that we can come together to create guidelines, but could not do so to prevent the creation of the groups of people whose treatment now demands them.

Adrian Burton



Somali refugees at a Dolo Ado camp in Ethiopia

For more on Farrah Mateen’s call for guidelines on neurological care in humanitarian settings see *JAMA Neurol* 2018; 76: 394–95