

# Neurologic Care of Forcibly Displaced Persons

## Emerging Issues in Neurology

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### Abstract

There is a growing number of forcibly displaced persons (FDPs) worldwide. With more than 100 million people forcibly displaced today, there is an urgent mandate to understand the neurologic care needs of this population and how neurologists and other health care workers can most effectively provide that care. In this Emerging Issues in Neurology article, we attempt to (1) define the scope of the problem of providing neurologic care to FDPs, (2) highlight commonly encountered clinical challenges related to neurologic care of FDPs, and (3) provide useful clinical information for neurologists and other clinicians who deliver care to FDPs with neurologic needs. We address the terminology of forcible displacement and how terms may differ across a person's migration journey. Common challenges encountered by FDPs with neurologic needs across settings include loss of support systems, loss of personal health information, language barriers and differing expression of symptoms, differing belief systems, epidemiologic patterns of disease unfamiliar to the clinician, and patients' fear and perceived risks of engaging with health systems. Practical approaches are shared for clinicians who encounter an FDP with a neurologic presentation. Finally, the article discusses many unmet neurologic needs of FDPs, which require significant investment. These include addressing lapses in neurologic care during displacement and understanding the effects of forcible displacement on people with chronic neurologic conditions. Future research and educational resources should focus on improving epidemiologic intelligence for neurologic conditions across geographies, developing curricula for optimizing the neurologic care of FDPs, and evaluating the most appropriate and effective uses of health technologies in humanitarian settings.

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## Glossary

AAN = American Academy of Neurology; ARV = antiretroviral; EIN = Emerging Issues in Neurology; FDP = forcibly displaced person; IDP = internally displaced person; LMICs = low- and middle-income countries.

Human-made conflicts, persecution, violence, and human rights violations continue to displace people globally.<sup>1</sup> The UN Refugee Agency reported that the number of forcibly displaced persons (FDPs) reached 100 million for the first time in May 2022, representing 1 in every 78 people worldwide.<sup>2</sup> Many host countries estimate even higher numbers of FDPs than are officially counted.<sup>3,4</sup>

The UN recognizes FDPs as refugees, asylum seekers, and internally displaced populations (IDPs). Asylum seekers and refugees are people who seek international protection due to persecution or fear of persecution under the 1951 Refugee Convention and its 1967 Protocol, with asylum seekers' claim under review by their host countries. Asylum seekers now represent around a sixth of FDPs worldwide.<sup>5</sup> IDPs are displaced people who have not crossed international borders and comprise approximately 60% of FDPs,<sup>5</sup> with substantial increases over the past 2 years.<sup>6</sup>

More than half of FDPs globally are children.<sup>6</sup> More than 80% of FDPs reside in low- and middle-income countries (LMICs). The highest number of refugees per capita resides in Lebanon, where 1 in every 5 inhabitants is a refugee. FDPs often have reduced access to health care, resulting from health infrastructure disruptions. The growing number of FDPs necessitates urgent, internationally coordinated efforts, including by neurologists.

## Manuscript Scope and Disclaimers

Emerging Issues in Neurology (EIN) articles, published by the American Academy of Neurology (AAN) and its affiliates, provide guidance to neurologists about new or emerging issues that have immediate implications for the care of patients with neurologic disorders. The intent is to provide informal guidance derived from expert consensus until an evidence base is established that can inform evidence-based recommendations. The information in an EIN article (1) should not be considered inclusive of all proper treatments or methods of care or as a statement of the standard of care, (2) is not continually updated, (3) does not mandate any particular course of medical care, and (4) is not intended to replace the independent professional judgment of the treating provider, as the information does not account for individual variation among patients. In all cases, decisions about patient care should be considered in the context of treating the individual patient.

The specific goals of this EIN article are (1) to define the scope of the problem of providing neurologic care to FDPs, (2) to highlight commonly encountered clinical challenges related to neurologic care of FDPs, and (3) to provide useful clinical

information for neurologists and other clinicians delivering care to FDPs with neurologic needs. The rise of armed conflict and entrenched violence and the recent rapid increase in the global population of FDPs compel further attention. The negative effects of forced displacement on the quality of neurologic care warrant discussion as an EIN article. This article was approved by the AAN Quality Committee on August 29, 2022, and by the AANI Board of Directors on September 16, 2022.

## Scope of Problem

Epidemiologic research and data on neurologic disorders in FDPs are very limited. There are few reports on optimized treatment approaches, educational modules, or pathways to neurologic care. Technologies that could improve neurologic care for FDPs, such as telemedicine, have not been monitored or evaluated. Global clinical data systems capture few of the many possible clinical presentations of neurologic disorders in FDPs. Given the high burden of neurologic disorders worldwide, neurologic disorders are likely untreated or undertreated in many FDPs. Important variables in the understanding of neurologic care of FDPs include the income of the FDP's country of origin, the income of the host country, health systems' capabilities, the FDP's residence in an urbanized setting or a camp setting, presence of neurologists in that setting, presence of neurologically educated frontline workers, the FDP's history of trauma and other comorbidities, and the duration of the displacement and the humanitarian crisis. There may be bidirectional relationships between neurologic disorders and forcible displacement. Neurologic disorders may prompt or prohibit displacement. Conversely, displacement may cause or contribute to a range of neurologic disorders, including injuries to the nervous system, nutritional deficiency-associated presentations, and recurrence of previously treated conditions such as seizures or functional disorders.

Underpinning these complexities is a dearth of neurologists in many LMICs.<sup>7</sup> Globally, an increasing, worrisome trend toward targeting of health care workers and hospitals during conflict exacerbates the shortage of medical expertise. Neurologists may be targeted by threats, arrest, or assassination in crisis settings.

Forcibly displaced populations may possess multiple sources of vulnerability. These include psychological and physical trauma; lack of adequate sanitation; food, water, and energy insecurity; temperature extremes; protracted journeys in precarious conditions; exposure to endemic diseases; exposure to rape, torture, or war crimes; stigmatization; and multiple displacements.

FDPs may ultimately repatriate, stay in a country of first asylum, become displaced again to another country of asylum, or resettle in a third country. Repeated displacement is a defining feature of some conflicts.<sup>8,9</sup> Negative health effects of displacement often continue after resettlement. Language barriers can continue to delay diagnoses,<sup>10</sup> and psychiatric effects persist, correlating with the length of stay at asylum centers.<sup>11</sup>

It is important to highlight that many terms used in discussions of forcible displacement have legal definitions. People identified as refugees, undocumented immigrants, or asylum seekers may all be seeking refuge and fleeing persecution for reasons of race, religion, nationality, membership in a particular social group, or political opinion—the distinction lies in legal circumstances. An individual could be undocumented (i.e., they do not have a legal right to remain in the country they are in), then become an asylum seeker, and then become an asylee or refugee.<sup>12</sup> In the United States, people may transition between dozens of visa types and legal designations on this path, and access to health care can vary accordingly. Health care workers who aim to provide high-quality neurologic care to FDPs require knowledge of the environmental, cultural, psychological, and legal issues frequently encountered by these patients.<sup>13</sup>

## What Is Reported

Neurologic diagnoses are common among FDPs. For example, neurologic diagnoses accounted for 17% of Iraqi refugees seeking medical care in Jordan following the Iraq War with 13% requiring referral to a neurologist.<sup>14</sup> In a study of emergency department visits in Germany in 2018, FDPs most commonly reported headache, had higher diagnosis rates of psychogenic nonepileptic seizures and psychiatric disorders, and waited longer to receive a diagnosis compared with the host population's patients.<sup>15</sup>

Common neurologic disorders, including headache, stroke, and epilepsy, predominate in most reports of neurologic presentations of FDPs. In refugee camps, epilepsy and seizures are by far the most common neurologic disorder recorded. Depending on the age structure of the population, dementia is also reported. CNS infections are reported but are generally uncommon in FDPs due to active surveillance, global vaccination programs, and testing. Traditional surveillance systems for highly contagious or transmissible neurologic infections, such as poliomyelitis and meningitis, occur in many tropical settings while programs for epilepsy, stroke, or cerebral palsy are generally absent.<sup>16</sup>

The global population is aging, resulting in a rise of non-communicable diseases such as hypertension, diabetes, obesity, and smoking-related disorders. In addition, FDPs have more frequent multimorbidity and higher incidences of headaches, musculoskeletal pains, and malnutrition-related conditions such as peripheral neuropathy.<sup>17-20</sup> Previously treated conditions, such as hypertension, may be more difficult to control during forced displacement.<sup>16</sup>

There is a growing burden of traumatic and posttraumatic conditions in FDPs. Exacerbations of chronic disorders, such as multiple sclerosis and epilepsy, may occur due to excessive stress and interrupted availability of maintenance medications.<sup>18,21,22</sup> Psychogenic nonepileptogenic seizures are also reported in FDPs.

FDPs experience infections that are less prevalent in the countries where they resettle, including reemerging infections, vaccine-preventable infections, or infections from different ecosystems.<sup>18,19</sup> Importantly, FDPs may be erroneously blamed for bringing infectious diseases into a new country, a source of stigmatization that should be handled carefully by treating clinicians.

## Common Challenges Related to Clinical Neurology

### Loss of Support Systems

Forcible displacement often fragments families and communities, which are important sources of economic, social, physical, and psychological support. Loss of support systems can be especially devastating for people already marginalized due to their ethnicity, religion, physical abilities, or economic status. The needs of FDPs with disabilities may be especially neglected without directed efforts to support them.<sup>23</sup> The separation of young children from their parents, planned or unplanned, can have harmful effects on children's neurodevelopmental trajectories and long-term mental health.<sup>24</sup>

### Loss of Personal Health Information

Displacement often occurs abruptly and may result in loss of key documents needed to verify identity and access available resources. FDPs may lose access to medical records delineating predisplacement medical conditions. Medical records from the home country may be destroyed, and the treating physicians may be untraceable. For example, people with epilepsy may present without details of their seizure semiology, prior investigations, or medication history. Separation of children from their primary caregivers may also result in a loss of the child's health information. New health care workers may struggle to assimilate available data into the best management plan.

### Language Barriers and Expression of Symptoms

Language barriers between health care workers and patients, which restrict information transfer and accurate understanding of patients' symptoms, are common when treating FDPs. Neurologically competent medical interpreter services are crucial for a specialty that relies heavily on patient histories. Without assistance, clinicians may ignore or misinterpret unfamiliar expressions of symptoms or illness experiences. Health care personnel with no training in neurology may be unable to provide even basic care for common neurologic conditions if key words are misunderstood.

## Differing Belief Systems

FDPs from some regions may hold traditional beliefs on health and disease that deter them from seeking care from allopathic, Western practitioners. Presentations may be delayed, and the patient's prior attempted treatments may be unfamiliar to clinicians. Seeking psychiatric care may be unacceptable in some cultures, leading to presentation to neurologists instead. Extensive communication and even new, atypical therapeutic approaches may be required before the patient and clinician can agree on treatments to try and who will provide them.

## Epidemiologic Differences in Disease

Local health care providers may be unfamiliar with conditions common to the FDPs' region of origin, delaying diagnosis or treatment. Specific examples include vaccination schedules in the country of origin, sanitation practices and exposure to specific infectious pathogens (e.g., *Taenia solium*), seasonal or recurrent infections (e.g., malaria), recreational activities and substances used (e.g., chewing tobacco), and access to specific health programs and medications.

## Fear and Risks to the Patient

Displacement may occur in situations of great risk to self and others. Forcible displacement increases the risk of financial exploitation and physical, psychological, and sexual abuse. These traumatic experiences increase vulnerability to future mental and physical health crises<sup>25</sup> including functional illnesses presenting with neurologic symptoms.<sup>24</sup> Patients may be reluctant to disclose these experiences, and establishing trust may take time.

## Practical Information and Clinical Approaches

When approaching the evaluation and treatment of FDPs, health care practitioners should ask: what is known? Ask directly for medical records—in many countries, patients carry their own. In building the clinical story, always use a medical interpreter if available. Even clinicians fluent in a language may be unfamiliar with specific terms used in the patient's local dialect. Consulting professionals from the displaced community can be particularly valuable to ensure important historical points are not missed. Beyond attaining information on the presenting condition, ask about the patient's recent experiences that may affect clinical care or assessment (e.g., interruption in treatment or rehabilitative process, loss of assistive devices, or loss of medications).

For people with a physical neurologic disability, are there specific needs that could compound acute care if interrupted? For those with neuromuscular disorders, do they have specific respiratory or feeding needs? Much can be attained from a careful clinical assessment, but the loss of a health history in a person with a complex medical background places the individual at increasing risk the longer the care is interrupted.

When caring for FDPs, neurologists should be aware that experiences from the premigration period, the migration journey, and postmigration resettlement can all be relevant to a patient's health care needs.<sup>26-28</sup> Neurologists should inquire about this full continuum of experiences. Premigration experiences may include exposures to physical and psychological trauma in the country of origin, social determinants of health in those countries, and the limitations of the health care infrastructure resulting in underdiagnosis or undertreatment of health conditions. The migration journey can involve malnutrition; dehydration; separation from family; exposure to new illnesses or traumas; and lack of medical, psychological, and dental care, all of which can vary according to the mode of transportation (e.g., by foot or by water), locations involved in the migration journey (e.g., refugee camps, detention centers, or precarious housing across different countries), and the duration of the journey. FDPs may spend years or decades living in camps, with the average length of time estimated to be 17 years for the 1 in 5 refugees who stay in those circumstances. Finally, postmigration factors may include family and neighborhood context, social position, social support and exclusion, language competence, discrimination, acculturative stress, and potential for detention.<sup>29</sup>

Neurologists should also adopt a trauma-informed approach. It can be particularly helpful to practice a strengths-based approach to care (e.g., recognizing that FDPs have drawn on significant strengths to have survived displacement and should not be reduced to their traumatic experiences), ask permission before discussing potentially difficult subjects to avoid retraumatization, and ensure that referral mechanisms are in place to treat trauma-related disorders that may arise in a clinical encounter.<sup>30</sup> Special populations include children, elderly patients, and pregnant patients. Women-led households, mature minors, and trafficked patients or those held against their will must be considered for any additional needs. Gender-based and sexual violence is a deliberate tactic of war, torture, and terror, and people with disabilities are especially at risk.<sup>31</sup>

Children may have little or no knowledge of their medical history and may have trouble articulating their needs. They may remain dependent on their caregiver to advocate for them, which can be difficult even for knowledgeable caregivers. Health care workers should document a child's clinical story as it unfolds and provide the child with that documentation to show to subsequent health care practitioners. The record should include what is known with confidence (e.g., this child has epilepsy and a recent infection), what is suspected (e.g., the events are most likely absence seizures), and what is not known (e.g., prior medications). Practitioners should consider and document who is with the child, who is acting as the child's caregiver, and any close loved ones they have recently lost. The clinical examination, acute findings, chronic issues, investigations completed, the results of those investigations, and future priorities for care should all be documented. Clinicians should be cautious about concluding



a child's cognitive level of functioning. Children may be emotionally closed off to strangers, and assumptions cannot be made about baseline and current level of functioning without significant assessment by trained personnel. In addition, they may have had limited access to high-quality education.

Neurologists have an essential role in providing expedited documentation of patient visits and keeping accurate records to the best of their abilities.<sup>32</sup> The dynamic nature of FDPs should lead to discussion about how to quickly provide a patient with medical records from the visit and whether neurologic follow-up is likely in the same location.

Several resources exist that may be helpful references when treating FDPs. Specific examples include online resources from the US Center for Disease Control and Prevention's *Yellow Book*, the European Centre for Disease Prevention and Control, the World Health Organization's *mhGAP Humanitarian Intervention Guide*, and the Global Polio Eradication Initiative. The UN Refugee Agency provides updates on current humanitarian situations and geographical context that may be helpful for neurologists who are unfamiliar with the circumstances that led a displaced patient to their care.

## Unmet Needs

At a policy level, much needs to be done for FDPs, including those with neurologic disorders and the high number of people at risk for them. In addition to the overall lack of resources for FDPs, particularly in exhausted health systems, specific unmet needs of clinical relevance to neurologists include the following.

### Addressing Lapses in Neurologic Care

Displacement often interrupts FDPs' access to medication and other long-term treatments. For example, FDPs may lose access to medications for managing Parkinson disease or secondary stroke prevention. Abrupt discontinuation of antiseizure medications is associated with status epilepticus and possibly death.<sup>33</sup> Lack of access to antiretroviral (ARV) medications for people living with HIV can result in disease progression, opportunistic infections, and risk of AIDS-related death.<sup>34</sup> Delayed or lapsed ARV treatment also increases the long-term risk of immune reconstitution inflammatory syndrome with ARV reinitiation and the development of HIV-associated cognitive disorder.<sup>35,36</sup> Recent humanitarian crises such as the crisis in Ukraine have also disrupted ongoing clinical trials of emerging therapies, with access to study sites becoming extremely challenging. Creating private-public partnerships for procurement and delivery of neurologic medications and updating Essential Medicines Lists for inclusion of these medications may help minimize disruptions over time.

### Understanding How Displacement Affects Chronic Neurologic Disorders

Closing the many knowledge gaps highlighted in this article requires funding for research on the pressing neurologic needs in FDPs. Research is needed on the neurologic effects of

humanitarian crises, including sleep deprivation, exacerbating headache, and increasing seizure frequency.<sup>37,38</sup> The role of physical pain and its undertreatment is also not well studied. The effects of the physical and mental stresses of displacement and the roles of food, water, and energy insecurity—as well as climate extremes—are underappreciated and difficult to quantify. Scales for measuring the neurologic burden and screening instruments for neurologic evaluations by frontline health care workers remain uncommon.

### Improving Epidemiologic Intelligence

FDPs often have decreased access to testing, vaccines, and disease surveillance. Highly mobile populations are not well studied, and information is not always shared between countries. Displacement may expose individuals to endemic infections for which they have limited or no immunity. For example, movement into malaria-endemic regions by nonimmune populations results in epidemic numbers of cases including cerebral malaria among both children and adults.<sup>39</sup> When treating FDPs, neurologists must expand their diagnostic reasoning to consider disorders that may occur in patients' countries of origin and countries traversed along the migration journey, at-risk age groups, and who has existing immunity to specific diseases. Even basic epidemiologic data in some settings could inform better neurologic care.

### Curricula Development

The scope, depth, and accessibility of curricula for neurologists on FDPs' care require considerable improvement. Efforts could include training modules in postgraduate neurology programs, dedicated teaching courses, continuing medical education for neurologists, programming for frontline health care workers without neurologic training, and incorporation of neurologists into training programs and rosters of consultants for humanitarian health care education. Bidirectional learning from frontline health care workers in humanitarian emergencies should occur, and lessons learned should be shared more broadly. Ideally, these educational modules should exist in multiple languages with field workers providing case-based insights.

### Appropriate Use of Technologies

Many emerging technologies show promise for improving care for FDPs including point-of-care testing strategies, mobile phone-based health initiatives, and electronic medical records systems. Teleconsults with neurologists have been attempted in some settings when the patient has complex needs or the diagnosis is unknown. Whether and when emerging technologies are useful in neurologic care, the security of online information systems, and how to implement these technologies in real time are understudied. Similarly, payment models, FDPs' care seeking, and dependence on internet-based sources for health information require centralization, quality control, and research.

### Roles of Health Care Organizations

Health care crisis response organizations—whether local, regional, national, or international—are often best equipped to

deliver health care services for FDPs whose needs are not met by the host country's existing health care system. This is especially true in the acute phase of the response. Specialty societies, such as the AAN, have important roles to play in the care of FDPs through raising awareness, offering education, advocating for resources and policy, coordinating efforts, developing leadership initiatives, and supporting research and guideline development.

In addition to creating a platform for neurologists to communicate ongoing challenges and solutions, task forces and committees should serve as platforms for action. Global partnerships with neurologists, supranational agencies, and nongovernmental organizations in the humanitarian field must continue.<sup>40,41</sup> Data on neurologic needs and care in the United States for FDPs are sparse. Headache, sleep disorders, head trauma, and dementia predominated in 1 retrospective study of 779 resettled refugees with neurologic disorders.<sup>42</sup> Many neurologists already care for FDPs in the United States in their daily practice, particularly neurologists in settings with higher numbers of resettled FDPs. Neurologists may also participate in the review of neurologic conditions in the form of medical affidavits. A retrospective cross-sectional study of 139 medical affidavits in the United States found that 43% of asylum seekers reported a history of head injury.<sup>43</sup> Dedicated services and resources at a national level specific to FDPs with neurologic needs have yet to be enshrined in the United States, leaving patients to the auspices of existing health infrastructure, individual advocacy groups, personal resources, and changing macro-level influences.

Health care workers, vaccinators, frontline aid workers, and medical facilities are sometimes the direct targets of armed conflict.<sup>32,44,45</sup> The safety and protection of people providing neurologic care must be prioritized as international organizations coordinate to address the needs of FDPs. Neurologists can be educated and prepared to maximize their personal safety and health in humanitarian settings. Given the changing landscape of forcible displacement, neurologists will continue to encounter FDPs, and many neurologists themselves could become forcibly displaced.

## Conclusions

The global FDP population is large and growing, and their neurologic needs are only partially understood. Neurologists and other health care workers caring for FDPs with neurologic disorders must be aware of the unique experiences associated with displacement. Careful reconstruction of FDPs' clinical histories is particularly important, as is ensuring a durable and portable record for patients who may be displaced multiple times. There are extensive research and education gaps in the clinical care of FDPs with neurologic disorders; these require a supportive policy framework and allocation of necessary resources.

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## Neurologic Care of Forcibly Displaced Persons: Emerging Issues in Neurology

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