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Practical needs and considerations for refugees and other forcibly displaced persons with neurological disorders: Recommendations using a modified Delphi approach

Shawheen Rezaei

Massachusetts General Hospital

Foksouna Sakadi General Hospital of National Reference

Fu-Liong Hiew Kuala Lumpur Hospital

Ildefonso Rodriguez-Leyva Hospital Central Dr. Ignacio Morones Prieto

Jera Kruja University of Medicine

See next page for additional authors

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RESEARCH ARTICLE

REVISED Practical needs and considerations for refugees and other forcibly displaced persons with neurological disorders: Recommendations using a modified Delphi approach [version

2; peer review: 2 approved]

Shawheen Rezaei 101, Foksouna Sakadi 102, Fu-Liong Hiew 103, Ildefonso Rodriguez-Leyva (104,5), Jera Kruja (106,7), Mohammad Wasay (108, Osheik AbuAsha Seidi ^{19,10}, Saad Abdel-Aziz¹¹, Shahriar Nafissi^{12,13}, Farrah Mateen 1,14. Global Working Group for Refugees with Neurological Needs

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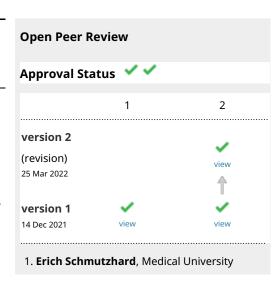
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Abstract

Background: There are >70 million forcibly displaced people worldwide, including refugees, internally displaced persons, and asylum seekers. While the health needs of forcibly displaced people have been characterized in the literature, more still needs to be done globally to translate this knowledge into effective policies and actions, particularly in neurology.

Methods: In 2020, a global network of published experts on neurological disease and refugees was convened. Nine physician experts from nine countries (2 low, 1 lower-middle income, 5 uppermiddle, 1 high income) with experience treating displaced people



¹Neurology, Massachusetts General Hospital, Boston, Massachusetts, 02114, USA

²General Hospital of National Reference, N'Djamena, Chad

³Neurology, Kuala Lumpur Hospital, Kuala Lumpur, Malaysia

⁴Universidad Autonoma de San Luis Potosi, San Luis Potosi, Mexico

⁵Neurology, Hospital Central Dr. Ignacio Morones Prieto, San Luis Potosi, Mexico

⁶Neurology, University of Medicine, Tirana, Tirana, Albania

⁷Neurology, University Hospital Center Mother Teresa, Tirana, Albania

⁸Neurology, Aga Khan University Hospital, Karachi, Pakistan

⁹University of Khartoum, Khartoum, Sudan

¹⁰Neurology, Soba University Hospital, Khartoum, Sudan

¹¹Médecins Sans Frontières, Amman, Jordan

¹²Neurology, Tehran University of Medical Sciences, Tehran, Iran

¹³Neurology, Shariati Hospital, Tehran, Iran

¹⁴Harvard Medical School, Boston, Massachusetts, 02115, USA

originating from 18 countries participated in three survey and two discussion rounds in accordance with the Delphi method.

Results: A consensus list of priority interventions for treating neurological conditions in displaced people was created, agnostic to cost considerations, with the ten highest ranking tests or treatments ranked as: computerized tomography scans, magnetic resonance imaging scans, levetiracetam, acetylsalicylic acid, carbamazepine, paracetamol, sodium valproate, basic blood tests, steroids and antituberculous medication. The most important contextual considerations (100% consensus) were all economic and political, including the economic status of the displaced person's country of origin, the host country, and the stage in the asylum seeking process. The annual cost to purchase the ten priority neurological interventions for the entire displaced population was estimated to be 220 million USD for medications and 4.2 billion USD for imaging and tests

Conclusions: A need for neuroimaging and anti-seizure medications for forcibly displaced people was emphasized. These recommendations could guide future research and investment in neurological care for forcibly displaced people.

Keywords

Neurology; Refugee; Asylum; Armed Conflict; Epilepsy: Diagnosis; Practice: Stroke: Headache

Innsbruck, Innsbruck, Austria

 Ibrahem Hanafi , Damascus University, Damascus, Syria
 University Hospital of Würzburg and Julius Maximilian University of Würzburg, Würzburg, Germany

Any reports and responses or comments on the article can be found at the end of the article.

Corresponding authors: Shawheen Rezaei (shawheenrezaei@gmail.com), Farrah Mateen (fmateen@mgh.harvard.edu)

Author roles: Rezaei S: Conceptualization, Investigation, Methodology, Project Administration, Writing – Original Draft Preparation, Writing – Review & Editing; Sakadi F: Data Curation, Investigation, Writing – Review & Editing; Hiew FL: Data Curation, Investigation, Writing – Review & Editing; Kruja J: Data Curation, Investigation, Writing – Review & Editing; Kruja J: Data Curation, Investigation, Writing – Review & Editing; Seidi OA: Data Curation, Investigation, Writing – Review & Editing; Seidi OA: Data Curation, Investigation, Writing – Review & Editing; Nafissi S: Data Curation, Investigation, Writing – Review & Editing; Mateen F: Conceptualization, Investigation, Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing;

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REVISED Amendments from Version 1

This version of the manuscript directly responds to the reviewers' comments. This includes mentioning the lack of solid epidemiological data for neurological disorders in humanitarian crises and acknowledging the protracted nature of conflicts may lead to even more lack of clarity on the epidemiology in these settings. In addition, we clarify that we focus only on concrete interventions and not human resources in these recommendations. Also, we explain that the prominence of anti-seizure medicines on the priority interventions likely reflects the high prevalence, common morbidity, and potential mortality of seizures/epilepsy in these settings as well as their high efficacy for treating seizures. We also mention that several anti-seizure medicines are used off label for various pain conditions that make them useful across several neurological presentations. Three new references were added, including the recommendations by Reviewer 2 that include examples from the Syrian situation.

Any further responses from the reviewers can be found at the end of the article

Background

There are more than 70 million forcibly displaced people worldwide according to the United Nations High Commissioner for Refugees (UNHCR), a number that is unprecedented in the history of the organization¹. This figure includes 41.3 million internally displaced people (individuals fleeing their homes due to persecution, war or violence, but who still remain within their country's border), 25.9 million refugees (individuals fleeing their country of origin due to persecution, war or violence, who have been granted refugee status under international law) and 3.5 million asylum seekers (individuals fleeing their country of origin due to persecution, war or violence, whose request for sanctuary has yet to be processed)1,2. Displaced people, due to the experiences of violence, famine, armed conflict and/or persecution associated with displacement, often face a set of challenges that are distinct from those of other patient populations³. Healthcare systems are also subject to increased pressure in times of conflict, when access to care can be weaponized against vulnerable populations and workplace violence can put healthcare workers' safety in jeopardy4,5. While the unique health needs of forcibly displaced people have been characterized in the literature, more still needs to be done on an international level to translate this knowledge into effective policies and actions, particularly in neurology⁶.

Although people are fleeing their homes in the largest numbers since World War II, there is a documented lack of international collaboration to address the health needs of forcibly displaced populations³. The neurologist community is poised to address this need through collaborative approaches. Especially in neurology, the treatment needs of forcibly displaced people are not well synthesized across locations and disorders. In large part, the epidemiology of neurological disorders in times of humanitarian crisis is unknown. There are few neurologists present in most humanitarian emergency settings, particularly in lower income settings. Since many conflicts are protracted, the situation is reported in snapshots but

not longitudinally, and neurologists themselves may flee. The published accounts available highlight the need for improved frameworks for understanding and treating the neurological conditions that come with displacement in more modern settings^{7–9}.

The determinants of neurological health are also being better recognized with time, noting that environmental conditions can further compound the lived experiences of refugees with neurological disorders. These other factors include - but are not limited to - malnutrition, climatic extremes, exposures to infections and toxins, lack of protections and security, poor sanitation, and generally unstable living conditions⁸⁻¹¹. The neurological needs of displaced people often overlap mental health conditions resulting from the trauma and stress of displacement, including post-traumatic stress, anxiety and depressive disorders, calling for more in-depth investigations of the needs of this population in light of their specific context¹²⁻¹⁴. Furthermore, systemic hurdles ranging from the lack of contextualized health education for refugees with neurological needs to the limited resources available in many countries of first asylum make quality healthcare less accessible to displaced people^{15–17}.

By directly confronting this situation, the neurologists and related providers of neurological care have an opportunity to address the neurological toll of complex humanitarian emergencies¹⁸. The development of a more complete vision for pragmatic actionable steps for neurological interventions will streamline healthcare systems and international actors approach to alleviating this high burden of disease. Although current care is reactive and responsive to needs as they arise, at best, future planning could lead to preparedness and avoidance of humanitarian crises compounding the burden of global neurological disease.

Our modified Delphi consensus method attempts to address the critical need to devise a baseline set of guidelines on implementing concrete neurological interventions for displaced people in complex humanitarian emergencies¹⁹.

Methods

The Delphi method

The Delphi method has been demonstrated to serve as an effective process for arriving at a consensus among a panel of experts in multiple disciplines^{20–22}. Through an iterative process, experts are requested to complete surveys individually and then participate in group discussions to provide feedback on the results of the survey, which has been shown to enable a group to reach a consensus swiftly²⁰.

An outline of the rounds of the modified Delphi method executed for this study is provided in Figure 1.

Study objective and protocols

The project included two full rounds of surveying and discussion in accordance with the Delphi method, with a final round survey that determined the working group-endorsed lists of

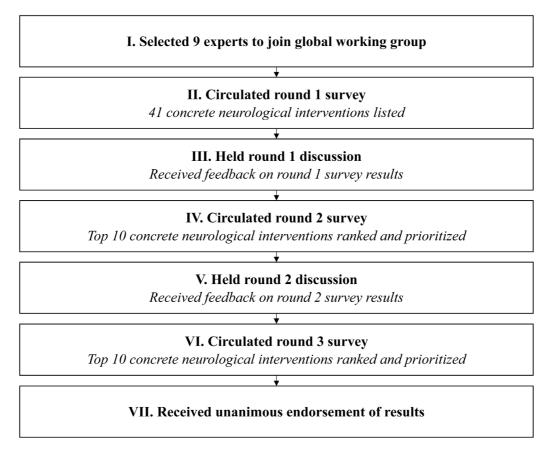


Figure 1. Delphi method flowchart.

contextual considerations (Table 1) and concrete neurological needs of displaced people globally (Table 2). The study was deemed exempt from formal review by the Mass General Brigham Institutional Review Board.

Member selection

In early February 2020, a list of 30 experts, primarily neurologists but also including non-neurologist physicians, was formed through an internet search through medical journal databases and professional websites. Expertise was determined by the individual's knowledge of the unique neurological needs of forcibly displaced people as demonstrated by research publications and self-reported clinical exposure to displaced populations and was not limited to neurologists. The population considered forcibly displaced for this study included people displaced due to persecution or conflict and excluded people displaced due to economic or climate reasons. This list was further narrowed to 16 experts based on their geographic location, which were invited to join the study. A Global Working Group of nine experts representing the Republic of Albania, the Republic of Chad, the Islamic Republic of Iran, the Hashemite Kingdom of Jordan, Malaysia, Mexico, the Islamic Republic of Pakistan, the Republic of the Sudan and the United States of America was formed (Table 3). Reasons for

nonparticipation of members of the initial 30 experts included insufficient exposure to displaced populations and an inability to participate regularly in the Delphi method process. The process did not specifically address the effects of Covid-19 but was carried out during the pandemic. Of the selected Global Working Group participants, six experts treat asylum seekers, nine treat refugees, and five treat internally displaced persons (Table 3).

Round one of the Delphi method

In mid-March, the round one survey was distributed to the Global Working Group. The survey requested each expert to provide their background information in addition to listing their experiences with displaced people. The main survey questions asked the experts to rank the top ten neurological interventions to address the neurological needs of displaced people, ignoring costs; to rank a list of demographic factors of displaced people that make the largest difference in providing neurological care; and to list other considerations that are important when assessing the needs of displaced people. The experts were informed that "concrete" refers to material interventions such as medical supplies (e.g.: phenobarbital, thiamine, head CT). Once all Global Working Group participants completed the round one survey, the results were circulated

Table 1. Ranking of other important considerations when treating neurological needs of displaced people.

Ranking	Consideration	Consensus (%)
1	Economic status of displaced person's host country	100*
2	Stage of displaced person in the asylum process	100*
3	Economic status of displaced person's country of origin	100*
4	Availability of neurological care	63
5	Social support for displaced people	63
6	Language translation challenges	50
7	Rehabilitation facilities	50
8	Care of women and children	38
9	Healthcare coverage in national system for displaced persons	38
10	Education on how to care for displaced people	25
11	Increased training of neurologists	25
12	Mobile care teams/telemedicine	25
13	Placement upon discharge from hospital	25
14	Support of scientific study projects on neurological pathologies	25
15	Cultural differences	13
16	Logistics between hospital and asylum center	13
17	Professional support for physicians on the field	13
18	Religious issues	13
19	Ambulances	0
20	Food quality	0
21	Sports and recreational facilities	0
22	Trauma and injury prevention	0

^{*}Consensus reached through round 1 discussion

to the group. A total of 41 concrete neurological needs were listed and 20 important issues that were ancillary to the actual provision of a treatment were listed by the Global Working Group participants. In early April, the round one discussion was convened via a face-to-face Zoom call to review the results of the survey, provide rationale for interventions listed, and provide suggestions to incorporate into the next round of the Delphi method.

Round two of the Delphi method

Based on the results from round one, 14 larger categories of neurological interventions were developed, under which 33 specific items were listed after feedback. The experts were then asked to select and prioritize a list of ten interventions from the total list of interventions established from the previous round. The experts were also asked to rank the interventions from 1–4 based on the degree of necessity (1- absolutely necessary to

4- nice to have). In late May, the round two discussion took place via a face-to-face Zoom call with seven of the experts to provide feedback on the results of the round two survey. A comprehensive list of specific items was established within each category, and the experts agreed to rate specific items instead of categories for the final survey.

Round three of the Delphi method

In early June, the round three and final survey was circulated among the experts. It requested that each expert rate 41 specific items on a scale of 0–100 independently, with 0 being not necessary and 100 being absolutely necessary for the treatment of displaced people. The ratings for these 41 interventions were then averaged from across the working group and ranked from highest mean rating to lowest. For select categories (anti-seizure, anti-headache/pain, neuro-psychiatric and cardiovascular/neurovascular), each expert was asked to select

Table 2. Complete ranked list of neurological interventions for displaced people.

Ranking	Intervention	Rating ¹
1	CT scan	90.9
2	MRI scan	89.8
3	Levetiracetam	89.1
4	Acetylsalicylic acid	86.6
5	Carbamazepine	86.3
6	Paracetamol	81.8
7	Sodium valproate	81.7
8	Basic blood tests	80.7
9	Steroids	79.4
10	Combined anti-tuberculous medications	78.0
11	Clopidogrel	76.8
12	Lamotrigine	76.7
13	Electroencephalogram	76.6
14	Blood pressure screening equipment	74.4
15	Escitalopram	73.4
16	Propranolol	73.3
17	Amitriptyline	73.2
18	Folate	73.0
19	Vitamin B12	72.4
20	Vitamin B complex	72.1
21	NSAID	71.8
22	Phenytoin	71.1
23	Statin	70.9
24	Fluoxetine	70.6
25	Vitamin B1	68.8
26	Vitamin B6	68.6
27	Pregabalin	68.0
28	Gabapentin	67.9
29	Electromyogram-Nerve conduction study	67.8
30	Parenteral Acyclovir	66.7
31	Levodopa-Carbidopa	65.1
32	Lumbar puncture sets	63.9
33	Vitamin D	63.2
34	Warfarin	62.4
35	Intavenous Immunoglobulins	60.1

Ranking	Intervention	Rating ¹
36	Hydrochlorothiazide	59.0
37	Opiate	52.6
38	Amantadine	48.4
39	Magnesium	45.3
40	Methylmalonic acid	37.3
41	Homocysteine	34.6

¹ Rating on a 0–100 scale, with 0 being not necessary and 100 being absolutely necessary for treating displaced people

the top priority medication when treating displaced people. The number 1 priority and number 2 priority items for each of these categories was documented based on the percent of working group members that reached consensus on a given intervention.

Cost assessment

A cost assessment was conducted for the top ten interventions, using a basic economic cost estimation model. The estimation for these interventions is provided in Table 4. These cost estimations used the most affordable price points available in the pharmaceutical market through online searches of goodrx.com in June 2020. The assessed price points were individual pricings and do not take into account large-scale price negotiations that an international organization could leverage. An illustrative dosage for each medication was selected based on prescribing patterns that are common for treating neurological conditions in adults. Treatment of a medicine for a chronic condition was estimated at one year. This assessment projected the population of displaced people needing care based on estimations made by a variety of sources such as the Center for Disease Control (CDC) and the World Health Organization (WHO). For imaging interventions, the percentage of displaced people requiring care was projected using the average MRI and CT scan usage estimates of >20 European countries from Eurostat. These data were used since many other countries do not have data collected or readily available on these interventions.

Results

Ranking of supplemental considerations important for neurological care

Throughout the iterations of surveying and discussions, the Global Working Group determined important contextual considerations ancillary to the provision of neurological care for displaced people that were not concrete neurological interventions. During the round one discussion, consensus was reached that the economic status of the displaced person's host country made the largest difference on the approach to providing neurological care to displaced people, followed by the stage of the displaced person in the asylum process and the economic status of the displaced person's country of origin. A list of contextual considerations when providing neurological care to

Table 3. Background information of Global Working Group participants?.

Participant	Country of residence	Specialty	Affiliations	Treat asylum seekers	Treat refugees	Treat internally displaced persons	Primary countries of origin of displaced people treated
Farrah Mateen	USA	Associate Professor of Neurology	Massachusetts General Hospital; Harvard Medical School	yes	yes	yes	Guinea, Sierra Leone, Syria, Iraq, Mexico
Foksouna Sakadi Chad	Chad	Neurologist	General Hospital of National Reference	yes	yes	no	Central African Republic, South Sudan, Sudan, Libya, Nigeria
Fu-Liong Hiew	Malaysia	Neurologist	Kuala Lumpur Hospital	yes	yes	no	Myanmar (Burma), Syria
Ildefonso Rodriguez-Leyva	Mexico	Professor of Neurology	Universidad Autonoma de San Luis Potosi; Hospital Central Dr. Ignacio Morones Prieto	yes	OU OU	yes	Mexico, various countries in Central and South America
Jera Kruja	Albania	Professor of Neurology	University of Medicine, Tirana; University Hospital Center Mother Teresa	OU	yes	no	Iran
Mohammad Wasay	Pakistan	Professor of Neurology	Aga Khan University Hospital	OU	yes	yes	Afghanistan, Myanmar (Burma), Pakistan
Osheik AbuAsha Seidi	Sudan	Professor of Neurology	University of Khartoum, Soba University Hospital	yes	yes	yes	Eritrea, Ethiopia, Sudan, South Sudan
Saad Abdel-Aziz	Jordan	Physician; Public Health Specialist	Médecins Sans Frontières (MSF) Jordan; Johns Hopkins Bloomberg School of Public Health	yes	yes	NO	Syria
Shahriar Nafissi	Iran	Professor of Neurology	Tehran University of Medical Sciences; Shariati Hospital	00	yes	yes	Afghanistan, Iraq, Iran

² Ordered alphabetically by first name

Table 4. Highest ranked neurological interventions for displaced people.

Rank	Intervention	Rating ³	Estimated % of population in need	Annual cost estimation (1,000 \$USD) ⁴		
Imaging and tests						
1	CT scan	90.9	8	2,200,000		
2	MRI scan	89.8	6	1,700,000		
3	Basic blood tests ⁵	80.7	20	320,000		
Medications and supplements						
1	Levetiracetam	89.1	0.4	31,000		
2	Acetylsalicylic acid	86.6	0.24	3,100		
3	Carbamazepine	86.3	0.4	47,000		
4	Paracetamol	81.8	3	46,000		
5	Sodium valproate	81.7	0.4	70,000		
6	Steroids	79.4	0.001	38		
7	Anti-tuberculous medication	78.0	0.13	24,000		

³ Rating on a 0-100 scale, with 0 being not necessary and 100 being absolutely necessary for treating displaced people

displaced people, ranked based on percent consensus that the intervention is a top consideration, is provided in Table 1.

Top neurological interventions for displaced people

A comprehensive, ranked list of 41 concrete neurological interventions for displaced people determined through the Delphi method is provided in Table 2. The top ten concrete neurological interventions to treat displaced people are provided in Table 4. They include two imaging interventions (CT scans and MRI scans) and three anti-seizure medications (levetiracetam, carbamazepine and sodium valproate).

For select categories of neurological interventions, the Global Working Group was asked to select the one medication they would use to treat displaced people. Table 5 provides the results of this prioritization, which was determined for anti-seizure, anti-headache/pain, neuropsychiatric, and cardiovascular/neurovascular treatments, along with cost estimations.

Assessing the costs of the intervention

As calculated in June 2020, the annual cost of providing the most important neurological interventions for the entire displaced population would be 220 million USD for medications and 4.2 billion USD for imaging and tests. The cost estimations for each of the most important neurological interventions are provided in Table 4 along with an estimated percent of displaced people in need of each intervention. This paper assumes a

monotherapy anti-seizure treatment. As such, an average of the annual cost estimations of the three anti-seizure medications in the top 10 list (levetiracetam, carbamazepine and sodium valproate) was used when calculating the total annual cost for medications

Discussion

Through this novel collaboration across several continents, the Global Working Group offers foundational recommendations on the most pressing neurological interventions. Though WHO guidelines for mostly psychiatric conditions have been released as the Mental Health Gap Action Programme (mhGAP), there are currently no registries, surveillance or standards for specifically treating the neurological needs of displaced people in humanitarian contexts²³. Calls for action such as the World Health Assembly's Intersectional Global Action Plan on Epilepsy and Other Neurological Disorders indicate growing interest in addressing these needs²⁴.

We build upon previously conducted economic evaluations of the neurological treatment of displaced people, which have been limited to micro-scale cost assessments of specific populations²⁵. As our cost assessment of top concrete neurological interventions indicates, the complete coverage of major neurological treatments among displaced people (such as seizures and chronic pain) would be relatively inexpensive. Especially in light of the high degree of disability caused by neurological

⁴ Estimation of annual cost of standard dosage/procedure for the percent of displaced population in need of a given intervention

⁵ Complete blood panel used as example of basic blood test.

Table 5. Top two priority treatments for select treatment categori
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Type of treatment	Top rated intervention	% consensus	Cost per pill (\$USD)
	1) Levetiracetam	44	0.15
Anti-seizure	1) Carbamazepine	44	0.23
	1) Ibuprofen ⁶	33	0.12
	1) Amitriptyline	33	0.17
Anti-headache/pain	1) Paracetamol	33	0.03
	1) Escitalopram	67	0.24
Neuro-psychiatric	2) Fluoxetine	33	0.12
Cardiovascular/	1) Acetylsalicylic acid	75	0.05
neurovascular	2) Clopidogrel	25	0.26

⁶ Ibuprofen selected as example of NSAIDs

conditions, this cost assessment suggests that focusing resources toward treating such conditions could be cost-effective and also dramatically improve the overall wellbeing of many displaced people. Emphasis on antiseizure medicines among the priority items listed underscores the need to better to epilepsy in this population, but also may reflect that these medications can be used "off label" in several cases for headache and other pain disorders.

It is also important to stress that the price points for these interventions may in fact be much lower in the context of treating displaced people, since much of this population resides in lower income countries where the costs of production are much lower than higher income countries, where data on medication and other procedures are more readily available. This price difference would particularly be important to consider in the case of MRI scans, CT scans, and basic blood tests, where the only data available factor in the cost of labor. This cost is much higher in a high-income country context and consequently may not accurately reflect the true cost that would be incurred in the context in which a displaced person is treated. Furthermore, this finding could also suggest that more cost-effective ways of implementing these procedures for displaced people-- such as the provision of portable MRIs currently being piloted in low-income contexts-- should be explored to ensure that a minimum viable procedure is in place for displaced persons, if the status quo is too expensive to execute^{26–28}.

Study design: strengths and limitations

There are several strengths to this study. There has not been an expert-proposed set of recommendations of top neurological interventions for displaced people to date. These results create a foundation for future research and engagement for neurological care for displaced people. The Delphi method enabled the Global Working Group members to respond not

only from their personal expertise in treating the neurological needs of displaced people but also from the insights from other members, improving the collective decision-making process. The geographic breadth of the Global Working Group members' countries of residence, coupled with the diverse nationalities and official statuses of the displaced people they treat, makes the scope of the results more broadly applicable across a wider array of contexts. By synthesizing the experiences of a representative sample of neurologists and other providers treating displaced people globally and providing an estimation for how much these interventions may cost, these results facilitate the action of international organizations and funders seeking to improve the condition of displaced people. The findings thus help fill a critical gap in the understanding of neurological needs of displaced people with a pragmatic and expert-sponsored set of concrete recommendations.

There are also several limitations to our approach. While the study incorporated the expertise of eight neurologists and one public health expert who have direct experience treating and assessing the neurological conditions of displaced people, inclusion of experts from more countries and other healthcare professions (such as nursing or emergency relief staff) could have added a greater variety of perspectives. Though the study devised a prioritized list for treating the neurological needs of displaced people generally, the various sub-populations (i.e., internally displaced people, asylum seekers, and refugees) may have distinct needs that merit individualized attention. We chose to inquire the most appropriate interventions agnostic to cost; other approaches could have included cost as an important, pragmatic consideration. However, ignoring cost in selection of priorities allows the list to remain relevant as costs change for medications and technologies over time. Similarly, we could have instead asked about common symptoms rather than neurological diseases in general. Given that many medications and interventions are overlapping across diseases, the current approach was selected.

The estimated costs for implementing top neurological interventions have many limitations, since there is a great degree of variation in the pricing of items based on the vendors within a certain country context and the availability of pricing data. Several of the interventions also have multiple dosages, which were not specified during the rounds of the Delphi method. This study also only considers the cost of a single MRI or CT scan and does not factor in the costs of establishing the infrastructure and maintenance required for such imaging. Finally, we focused the task on "concrete interventions" rather than for example, the cost of training a new neurologist or another health care worker for the humanitarian setting. Human resources are of high value but were considered outside of the scope of the present consensus recommendations.

Future directions

There are several steps that could be taken to act upon these recommendations. Since several of the items selected as most important through the Delphi method process are preliminarily estimated to be relatively inexpensive, funders that support relief aid for displaced people could allocate a portion of their budget for neurological treatments according to these cost estimations. International organizations addressing the needs of displaced people must then source these items from vendors in the regions in which they operate and ensure that supply chains exist to meet the needs on the ground. Challenges with availability of certain medications in specific country

contexts exist, in light of the differing Essential Medicine Lists across countries.

Beyond funding and acquiring the appropriate material interventions, organizations must also take into account the present shortage of neurology expertise in the frontlines of care provision. Improving neurology training curricula to better account for the most prevalent neurological needs during crisis, for example, could help improve workforce capacity²⁹. Aside from educating more healthcare providers on the diagnosis of basic neurological conditions or training more neurologists to specifically care for displaced people, relief organizations could also allocate a portion of their budgets to promote the access and use of telehealth technology to connect frontline aid workers providing direct care to displaced people with neurologists skilled in specialized diagnoses and determining the appropriate treatment plan³⁰. If these steps are taken to ensure the adequate sourcing of interventions for persons with neurological disorders in humanitarian settings, the international community could make great strides toward improving the situation for forcibly displaced people worldwide.

Data availability

Figshare: Neurological Needs of Refugees Round 3 Survey. DOI: https://doi.org/10.6084/m9.figshare.17124125.v1.

Data are available under the terms of the Creative Commons Zero "No rights reserved" data waiver (CC BY 4.0 Public domain dedication).

References

- UNHCR: Figures at a Glance. Last accessed: 24 June 2021. Reference Source
- UNHCR: What is a Refugee? Last accessed: 24 June 2021. Reference Source
- Matlin SA, Depoux A, Schutte S, et al.: Migrants' and refugees' health: towards an agenda of solutions. Public Health Rev. 2018; 39: 27. Publisher Full Text
- Fouad FM, Sparrow A, Tarakji A, et al.: Health workers and the weaponisation
 of health care in Syria: a preliminary inquiry for The Lancet-American
 University of Beirut Commission on Syria. Lancet. 2017; 390(10111):
 2516–2526.
 - PubMed Abstract | Publisher Full Text
- Mohamad O, AlKhoury N, Abdul-Baki MN, et al.: Workplace violence toward resident doctors in public hospitals of Syria: prevalence, psychological impact, and prevention strategies: a cross-sectional study. Hum Resour Health. 2021; 19(1): 8.
 - PubMed Abstract | Publisher Full Text | Free Full Text
- Müller M, Khamis D, Srivastava D, et al.: Understanding Refugees' Health. Semin Neurol. 2018; 38(2): 152–162.
 PubMed Abstract | Publisher Full Text
- Mateen FJ, Carone M, Nyce S, et al.: Neurological disorders in Iraqi refugees in Jordan: data from the United Nations Refugee Assistance Information System. J Neurol. 2012; 259(4): 694–701.
 PubMed Abstract | Publisher Full Text
- Fu Liong H, Santhi DP, Shanthi V, et al.: Myanmarese Neuropathy: Clinical Description of Acute Peripheral Neuropathy Detected among Myanmarese Refugees in Malaysia. Int Sch Res Notices. 2014; 2014: 187823. PubMed Abstract | Publisher Full Text | Free Full Text

- Mateen FJ, Carone M, Haskew C, et al.: Reportable neurologic diseases in refugee camps in 19 countries. Neurology. 2012; 79(9): 937–940.
 PubMed Abstract | Publisher Full Text
- Burton A: Meeting the neurological needs of refugees and other forcibly displaced people. Lancet Neurol. 2019; 18(6): 524–525.
 PubMed Abstract | Publisher Full Text
- Wasay M, Mushtaq K: Health issues of internally displaced persons in Pakistan: preparation for disasters in future. Am J Disaster Med. 2010; 5(2): 126–128. PubMed Abstract
- Mujeeb A: Mental health of internally displaced persons in Jalozai camp, Pakistan. Int J Soc Psychiatry. 2015; 61(7): 653–659.
 PubMed Abstract | Publisher Full Text
- Scoglio AAJ, Salhi C: Violence Exposure and Mental Health Among Resettled Refugees: A Systematic Review. Trauma Violence Abuse. 2020; 22(5): 1192–1208.
 - PubMed Abstract | Publisher Full Text
- 14. Satinsky E, Filippou TA, Kousoulis AA: Multiculturalism and Compassion: Responding to Mental Health Needs Among Refugees and Asylum Seekers Comment on "A Crisis of Humanitarianism: Refugees at the Gates of Europe". Int J Health Policy Manag. 2019; 8(12): 734–736. PubMed Abstract | Publisher Full Text | Free Full Text
- Sauerbier A, Macerollo A, Györfi O, et al.: Insufficient global health education in European neurological post-graduate training: a European Association of Young Neurologists and Trainees survey. Eur J Neurol. 2016; 23(11): 1680–1683.
 PubMed Abstract | Publisher Full Text
- 16. Heenan RC, Volkman T, Stokes S, et al.: 'I think we've had a health screen':

- New offshore screening, new refugee health guidelines, new Syrian and Iraqi cohorts: Recommendations, reality, results and review. *J Paediatr Child Health*. 2019; **55**(1): 95–103.
- PubMed Abstract | Publisher Full Text
- Glennerster R, Hodson N: Confused out of care: unanticipated consequences of a 'Hostile Environment'. J Med Ethics. 2020; 46(3): 163–167.
 PubMed Abstract | Publisher Full Text
- Mateen FJ: Neurological disorders in complex humanitarian emergencies and natural disasters. Ann Neurol. 2010; 68(3): 282–294.
 PubMed Abstract | Publisher Full Text
- Mateen FJ: Toward Minimum Standards Guidelines for the Delivery of Neurological Care in Complex Humanitarian Settings. JAMA Neurol. 2019; 76(4): 394–395.
 - PubMed Abstract | Publisher Full Text
- Okoli C, Pawlowski SD: The Delphi method as a research tool: an example, design considerations and applications. Inf & Manag. 2004; 42(1): 15–29.
 Publisher Full Text
- Cohen SP, Bhaskar A, Bhatia A, et al.: Consensus practice guidelines on interventions for lumbar facet joint pain from a multispecialty, international working group. Reg Anesth Pain Med. 2020; 45(6): 424–467. PubMed Abstract | Publisher Full Text | Free Full Text
- 22. Sá Dos Reis C, Gremion I, Richli Meystre N: Consensus about image quality assessment criteria of breast implants mammography using Delphi method with radiographers and radiologists. *Insights Imaging*. 2020; 11(1): 56.
 - PubMed Abstract | Publisher Full Text | Free Full Text
- 23. WHO: mhGAP Mental Health Gap Action Programme. Last accessed: 24 June

- 2021. Reference Source
- World Health Assembly: Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 - 2031. Last accessed: 24 June 2021. Reference Source
- McKenzie ED, Spiegel P, Khalifa A, et al.: Neuropsychiatric disorders among Syrian and Iraqi refugees in Jordan: a retrospective cohort study 2012-2013. Confl Health. 2015; 9: 10. PubMed Abstract | Publisher Full Text | Free Full Text
- Shen FX, Wolf SM, Bhavnani S, et al.: Emerging ethical issues raised by highly
 portable MRI research in remote and resource-limited international
 settings. Neuroimage. 2021; 238: 118210.
 PubMed Abstract | Publisher Full Text | Free Full Text
- Cooley CZ, McDaniel PC, Stockmann JP, et al.: A portable scanner for magnetic resonance imaging of the brain. Nat Biomed Eng. 2021; 5(3): 229–239.
 PubMed Abstract | Publisher Full Text | Free Full Text
- Wald LL, McDaniel PC, Witzel T, et al.: Low-cost and portable MRI. J Magn Reson Imaging. 2020; 52(3): 686–696.
 PubMed Abstract | Publisher Full Text
- Latifeh Y, Hanafi I, Alhoulaiby S, et al.: Crisis-based psychiatry curriculum update: A cross-sectional study and an expert reflection from Syria. Asian J Psychiatr. 2021; 61: 102681.
 PubMed Abstract | Publisher Full Text
- Saadi A, Mateen FJ: International Issues: Teleneurology in humanitarian crises: Lessons from the Médecins Sans Frontières experience. Neurology. 2017; 89(3): e16–e19.
 PubMed Abstract | Publisher Full Text

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Version 2

Reviewer Report 25 March 2022

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Ibrahem Hanafi 🗓



- ¹ Division of Neurology, Department of Internal Medicine, Faculty of Medicine, Damascus University, Damascus, Syria
- ² Department of Neurology, University Hospital of Würzburg and Julius Maximilian University of Würzburg, Würzburg, Germany

Many thanks for addressing my points, and congratulations on your excellent report. I have no further comments.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Internal medicine, Neurology, Neuroscience, Evidence-based medicine, Deep brain stimulation, Movement disorders

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 07 March 2022

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Ibrahem Hanafi 🗓



Thank you for considering me for reviewing your high-quality, well-presented manuscript. This novel report is of a great value and conveys important messages to neurologists and organizations working with displaced populations and worldwide. It is well written and provides sufficient details about the methodologies, which robustly support the illustrated conclusions. The panel is limited to nine participants, but they reflect a variety of experiences with displaced people worldwide, which intensify the generalizability of the findings.

I just have a few suggestions and concerns that I think might answer some doubts from readers when adequately managed.

Two points were in my opinion overlooked in the introduction, which are the lack of specialized neurologists in areas of conflict and the lack of epidemiological reports published during times of war. For instance, physicians including neurologists in Syrian centers dropped during the first few years of war (Fouad *et al.*, 2017^{1}), which put more pressure and drained the capacities of the other remaining doctors impacting the quality of care (Mohamad *et al.*, 2021^{2} and Hanafi *et al.*, 2021^{3}).

Although, esteemed recommendations on increasing neurology experts on the frontlines and telemedicine were raised. Readers might be additionally curious about the opinions of the panel regarding the extent of experience lacking in treating displaced populations, and how they would prioritize increasing the number of neurologists in comparison with the other logistic needs presented on the manuscript. Additionally, one further possible future perspective of the manuscript can be suggesting a modulation of the neurology curriculum of med-schools (e.g., increasing the training hours of more prevalent disorders) in areas where a high percentage of displaced populations is perceptible (Latifeh *et al.*, 2021⁴).

I believe readers with rather limited clinical experience, like me, might wonder about the reason behind the detailed depiction of antiepileptic drugs while several of them can be used interchangeably in places with limited resources. In contrast, I see that the authors combined all basic blood tests in one category. May the authors please provide more information on the reason behind that? Based on that, it is also not very clear to me whether the estimation of population in need (table 4) for the three antiepileptic drugs overlap or sum up?

I have a minor wonder regarding the following sentence: "An illustrative dosage for each medication was selected based on prescribing patterns that are common for treating neurological conditions in adults.". Although the illustrative dosage concept is understandable and necessary in such kinds of analysis, I wonder specifically about the long-term medications like antiepileptic drugs. What is generally the time window (i.e., length of therapy) considered when estimating the cost?

I have another concern regarding the cost estimation of the imaging interventions. The study says they were projected from estimates in European countries. However, more details on that projection can be of high importance to the readers. Would the esteemed opinions of the authors agree that imaging studies required in areas of conflicts should be substantively higher than the

¹ Division of Neurology, Department of Internal Medicine, Faculty of Medicine, Damascus University, Damascus, Syria

² Department of Neurology, University Hospital of Würzburg and Julius Maximilian University of Würzburg, Würzburg, Germany

ones ordered in the relatively safe Europe during the last few decades? Would they also agree that the ratio CT:MRI scans might deviate for the displaced populations from other stable wealthy populations?

I would add one point to the limitations that were adequately discussed by the authors. Although the experience of the panel allows them to speak on refugees, asylum seekers, and internally displaced populations (table 3), the article does not present any divergence of the opinions between the three groups, mixing all the views in one category that might be heterogenous regarding some points of the analysis.

Nevertheless, these suggestions do never affect my recommendations to index this valuable and vital article that drops attention to the neurological care of vulnerable populations and tries to alleviate their suffering worldwide.

References

- 1. Fouad F, Sparrow A, Tarakji A, Alameddine M, et al.: Health workers and the weaponisation of health care in Syria: a preliminary inquiry for The Lancet –American University of Beirut Commission on Syria. *The Lancet*. 2017; **390** (10111): 2516-2526 Publisher Full Text
- 2. Mohamad O, AlKhoury N, Abdul-Baki M, Alsalkini M, et al.: Workplace violence toward resident doctors in public hospitals of Syria: prevalence, psychological impact, and prevention strategies: a cross-sectional study. *Human Resources for Health*. 2021; **19** (1). Publisher Full Text
- 3. Hanafi I, Kassem L, Hanafi M, Ahmad S, et al.: Medical research conduct and publication during higher education in Syria: attitudes, barriers, practices, and possible solutions. *Research Square*. 2021. Publisher Full Text
- 4. Latifeh Y, Hanafi I, Alhoulaiby S, Alahdab F: Crisis-based psychiatry curriculum update: A cross-sectional study and an expert reflection from Syria. *Asian J Psychiatr*. 2021; **61**: 102681 PubMed Abstract | Publisher Full Text

Is the work clearly and accurately presented and does it cite the current literature? Yes

Is the study design appropriate and is the work technically sound? Yes

Are sufficient details of methods and analysis provided to allow replication by others? Partly

If applicable, is the statistical analysis and its interpretation appropriate? Yes

Are all the source data underlying the results available to ensure full reproducibility? Yes

Are the conclusions drawn adequately supported by the results? Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Internal medicine, Neurology, Neuroscience, Evidence-based medicine, Deep brain stimulation, Movement disorders

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 12 Mar 2022

Farrah Mateen, Massachusetts General Hospital, Boston, USA

We thank the reviewer for these suggestions. Each of the queries has been addressed in the new version of the manuscript. The section on the update for readers details these changes. Specifically, we updated the introduction to include the very important points that: (1) the epidemiology of neurological disorders are not well documented in humanitarian crises; (2) the number of neurologists in most armed conflicts is very few and may become fewer in times of conflict; (3) conflicts/humanitarian emergencies can be protracted and data may be a snapshot of a more longitudinal process; and (4) health care facilities and workers can be targets of armed conflict.

Several references (as recommended) were added to include important data from the Syrian situation.

The length of time for estimating medicines' costs for chronic conditions (e.g. epilepsy) was one year.

The importance of antiseizure medicines was apparent in this consensus process. We include some potential explanations in the paper: (1) the importance of epilepsy as a treatable and disabling condition, and (2) the use of some of these medicines for dual purposes, such as treatment of comorbid pain.

We have our raw data available on figshare which may provide some elements of heterogeneity in the process. Finally, we clarify that our interventions for prioritization are "concrete" and we did not include purchase of human resources for health (e.g. training a new neurologist) in that prioritization, considering separate from the current process. Thank you for your helpful comments and sharing your knowledge on this topic.

Competing Interests: No competing interests were disclosed.

Reviewer Report 03 March 2022

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Erich Schmutzhard

Neurological Intensive Care Unit, Department of Neurology, Medical University Innsbruck,

Innsbruck, Austria

In a time, when more than one percent (1%) of the world's population has to be perceived as forcibly displaced it is highly in time that the medical community, including neurologists from all over the world, are aware and must be made aware of diseases and their emergency diagnostic and therapeutic management steps in order to allow – according to Hippocrates – the best possible management of all those being in need. The authors, working in African, Asian, Northand Central American and European countries clearly show in this manuscript that they are aware of these needs and, even more, are well aware that this knowledge needs to be spread amongst the entire community of neurologists and medical doctors respectively.

Therefore, I suggest indexing this well-written and highly needed manuscript as it stands.

Is the work clearly and accurately presented and does it cite the current literature? $\mbox{\em Yes}$

Is the study design appropriate and is the work technically sound? Yes

Are sufficient details of methods and analysis provided to allow replication by others? Yes

If applicable, is the statistical analysis and its interpretation appropriate? Yes

Are all the source data underlying the results available to ensure full reproducibility? γ_{es}

Are the conclusions drawn adequately supported by the results? $\forall a \in A$

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Neurology, Tropical Medicine, in particular Tropical Neurology, Emergency and Critical Care Neurology

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 12 Mar 2022

Farrah Mateen, Massachusetts General Hospital, Boston, USA

The authors thank the reviewer for his review and thoughtful comments.

Competing Interests: No competing interests were disclosed.