

# **Mental health and quality of life of individuals with epilepsy during the war in Ukraine**

Andriy Dubenko<sup>1</sup>, Rinaldo Morelli<sup>2</sup>, J Helen Cross<sup>3</sup>, Julie Hall<sup>2</sup>, Volodymyr Kharytonov<sup>4</sup>, Rosa Michaelis<sup>5</sup>, Samuel Wiebe<sup>6</sup>, on behalf of the ILAE Emergency Task Force for Ukraine

## **Affiliations**

<sup>1</sup> Institute of Neurology, Psychiatry and Narcology of NAMS of Ukraine, Ukraine.  
[adneuro1801@gmail.com](mailto:adneuro1801@gmail.com)

<sup>2</sup> R Morelli: International League Against Epilepsy. [morellird@gmail.com](mailto:morellird@gmail.com)

<sup>2</sup> J Hall: International League Against Epilepsy. [jhall@ilae.org](mailto:jhall@ilae.org)

<sup>3</sup> UCL NIHR BRC Great Ormond Street Institute of Child Health, London, UK.  
[h.cross@ucl.ac.uk](mailto:h.cross@ucl.ac.uk)

<sup>4</sup> Child Psychiatry Department, Clinical Hospital "Psychiatry", Kyiv, Ukraine.  
[vkharytonov69@gmail.com](mailto:vkharytonov69@gmail.com)

<sup>5</sup> Ruhr-Epileptology, Department of Neurology, University Hospital  
Knappschaftskrankenhaus Bochum, Ruhr University Bochum, Bochum, Germany  
[rosa.michaelis@kk-bochum.de](mailto:rosa.michaelis@kk-bochum.de)

<sup>6</sup> Department of Clinical Neurosciences, University of Calgary, Canada.  
[swiebe@ucalgary.ca](mailto:swiebe@ucalgary.ca)

## **Corresponding author:**

Samuel Wiebe:  
Epilepsy programme, Rm C-1223  
Foothills Medical Centre  
1403-29 St NW, Calgary, Alberta, Canada T2N 2T9  
Phone: (403) 944-8534 Fax: (403) 283-2270  
[swiebe@ucalgary.ca](mailto:swiebe@ucalgary.ca)

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## **Abstract**

*Objective:* To investigate the repercussions of the war in Ukraine on people with epilepsy (PWE), focusing on access to healthcare, seizure control, quality of life (QOL), psychological distress, anxiety, and depression; and to identify the key factors influencing these measures.

*Methods:* Consecutive PWE age  $\geq 18$  years, presenting to one of seven health centers across Ukraine were invited to complete a self-administered survey in 2023. The survey gathered information on clinical and demographic aspects, geographic displacement, and access to care and medications. It also contained five valid questionnaires exploring psychological distress (Kessler-10), quality of life (EQ-5D-5L), depression (NDDIE), anxiety (HADS-A), and epilepsy severity (GASE scale). Multivariate linear regression models assessed the relationship between measures of mental health and QOL and their potential predictors. Ethical approval was obtained from the Institute of Neurology, Psychiatry and Narcology of NAMS of Ukraine, Ukraine.

*Results:* Among 305 participants (mean age 38 years), 40% were female, and 44% had to change residence because of the war. Seizures worsened during the war in 52% of those with active epilepsy and 42% of those with well-controlled epilepsy. Difficulties accessing health care and antiseizure medications occurred in 25% and 34% of PWE, respectively, and was worse among those who were displaced. According to the mental health instruments, 46% suffered psychological distress, 62% experienced anxiety, 50% were depressed, and 59% rated their epilepsy as somewhat severe or worse. Statistically significant predictors of psychological distress, anxiety and depression included female gender, more severe epilepsy, increased seizures during the war, and requiring mental health support.

*Significance:* The war significantly disrupted access to healthcare and availability of medication in PWE, who suffer from significant anxiety, depression, and psychological distress. We identify high-risk factors that can guide resource allocation for prevention and treatment.

**Keywords:** mental health, quality of life, armed conflict, Ukraine

## **Introduction**

Armed conflicts disrupt the infrastructure and societal cohesion upon which the effective delivery of healthcare crucially relies. Global burden of disease studies demonstrate that armed conflicts result in significant deterioration in mental health and non-communicable disorders, a decrease in life expectancy and a marked increase in disability adjusted life years<sup>1</sup>. This affects the most vulnerable, frail individuals and those suffering from chronic conditions, such as epilepsy, whose precarious health balance depends on a steady and reliable supply of healthcare services and therapies. For people with epilepsy (PWE), the deprivation of reliable access to healthcare and medications, upon which seizure control depends, can be catastrophic. Moreover, heightened stress levels, deteriorating mental health, and reduced access to care exacerbate both the frequency and severity of seizures<sup>2,3</sup>. This underscores a pressing demand for bolstered support networks, mental health experts<sup>4</sup>, specialized care, and hospital-based treatments—resources that are often in short supply amid widespread armed conflicts. A detrimental cycle unfolds, where escalating healthcare requirements clash with diminishing healthcare resources. Recognizing the profound repercussions of conflict on the mental well-being and overall quality of life (QOL) of people with epilepsy (PWE) is paramount. This understanding is crucial for prioritizing healthcare delivery and support initiatives effectively.

Previous research has demonstrated high levels of psychological distress and a heightened burden of non-communicable disorders in conflict areas in Ukraine<sup>5,6</sup>. However, none has focused specifically on people suffering from epilepsy. Based on personal communication from members of the Ukrainian League Against Epilepsy, it is estimated that between 100,000 to 130,000 adults and children with epilepsy have been displaced due to the war. Approximately half of these individuals have been internally displaced within Ukraine, while the other half have sought refuge in other countries. Our objective was to investigate the repercussions of the war in Ukraine on PWE, focusing on their access to healthcare, perception of seizure control, QOL, and levels of psychological distress, anxiety, and depression. Additionally, we aimed to identify the key factors influencing these measures most significantly. We hypothesized that psychological distress, anxiety, depression, and QOL would be adversely affected by factors such as being displaced because of the war, disruption of access to healthcare and medications, limited availability of mental health support services, and increased severity of epilepsy.

## **Materials and Methods**

We used a self-administered, user-friendly paper-and-pencil cross-sectional survey method, distributed to PWE accessing healthcare centers across seven regions in Ukraine, spanning from February to June 2023, one year into the war. Ethical approval was obtained from the Institute of Neurology, Psychiatry and Narcology of NAMS of Ukraine, Ukraine. The purpose of study was explained to patients before consent was

obtained for their voluntary participation. Personal identification information was not captured in the questionnaire.

### **Patient population**

We included people with any type of epilepsy aged  $\geq 18$  years and able to self-complete a simple survey. Consecutive patients presenting to a health center were invited by healthcare providers to complete the self-administered survey and to provide informed consent. A convenience sample size of 300 patients had 90% power to detect a small to medium effect size (R-Squared = 0.07) in multivariate regression models assessing 10 independent variables, with alpha set at 0.05.

### **Survey instruments**

A team consisting of health professionals directly involved in caring for PWE in Ukraine, together with members of the Ukraine emergency response task force of the International League Against Epilepsy (ILAE) iteratively designed the survey tool. This consisted of a 16-item questionnaire assessing patient demographics, internal and external geographic displacement, disruptions in access to regular healthcare, mental health services and medications, exacerbation of seizures, and type and number of antiseizure medications (ASMs) used. In addition, it contained five validated scales carefully selected to evaluate the mental health state and quality of life of PWE in Ukraine. Depressive symptom severity was assessed with the Neurological Disorders Depression Inventory for Epilepsy (NDDIE) a validated 6-item instrument with 4-point

Likert-like response options used to screen for major depressive disorder and suicidality in PWE, with total scores ranging from 6 to 24. A total score  $\geq 13$  predicts major depressive disorder<sup>7</sup> and a score of  $\geq 3$  in item number 4 predicts suicidality<sup>8</sup>. Anxiety levels were measured using the Hospital Anxiety and Depression Scale-Anxiety (HADS-A), a validated 7-item scale with 4-point response items used to screen for anxiety in PWE<sup>9,10</sup>, with total scores ranging from 0 to 21. As previously recommended, we categorized HADS-A scores into three levels: 0-7: normal, 8-10: mild anxiety, 11-21: moderate to severe anxiety<sup>9</sup>. To capture non-specific psychological distress experienced over the past month we used the Kessler 10 (K10)<sup>11</sup>, a validated, 10-item scale with 5-point response options with scores ranging from 10 to 50, which has been used in several studies in Ukraine<sup>5,6</sup>. We categorized psychological distress into four score levels of K10, as per the Australian population health survey ([https://www.worksafe.qld.gov.au/\\_data/assets/pdf\\_file/0010/22240/kessler-psychological-distress-scale-k101.pdf](https://www.worksafe.qld.gov.au/_data/assets/pdf_file/0010/22240/kessler-psychological-distress-scale-k101.pdf)): 10-19, 20-24, 25-29, and 30-50, respectively denoting likely to have no, mild, moderate and severe psychological distress. Health state valuation/utility was used as a metric of QOL and was assessed with the EQ-5D-5L, a widely used instrument for measurement of health states scored on 5 levels across 5 dimensions, with index values ranging from -0.523 to 1.00; as well as the EQ-VAS, a health state visual analogue rating scale with scores ranging from 0=worst possible health, to 100=best possible health<sup>12</sup>. The EQ-5D-5L index value was calculated using Polish population norms because, among countries with available population norms, the sociodemographic characteristics of Poland most closely mirrored those of Ukraine. To assess patient-perceived severity of epilepsy we used the Global Assessment of Severity of Epilepsy (GASE) scale, a validated, 7-point, single-item global rating of severity of

epilepsy with response options ranging from 1= not severe at all to 7 = extremely severe<sup>13,14</sup>. These tools were chosen based on their psychometric properties, feasibility and ease of use, and applicability to the study's objectives. Because time was of the essence, a rapid translation process was undertaken for the GASE and NDDIE instruments, which were translated to Ukrainian by an independent observer and back translated to English by a separate individual to ensure accuracy. For other instruments, previously validated Ukrainian versions were in place. The questionnaire and set of instruments underwent final assessment for content validity, clarity, and relevance by ILAE task force members.

The final questionnaire was disseminated to healthcare professionals providing care to PWE in cities across seven regions in Ukraine, who invited patients attending health centres for their usual medical care, to complete the survey. Data collection was carried out over a period of 5 months in 2023. The questionnaire was self-administered and completed by patients.

Action on instrument scores indicating severe psychological distress or identifying patients at high risk was an important consideration. The ability to intervene was severely hampered by the displacement and the war. However, we identified cut-off scores for various instruments that signified high risk or severe psychological distress and communicated these to referring clinicians. For example, to ensure proactive clinical intervention for patients exhibiting symptoms of depression or suicidality, the recruiting clinician received notifications when a patient's scores in the NDDIE suggested a heightened likelihood of such conditions. These notifications included the subject's ID number from the database, enabling the clinician to promptly address the patient's needs.



## **Analysis**

Descriptive statistics were calculated for demographics, quality of life, epilepsy severity, psychological distress, anxiety and depressive symptom severity. Pairwise comparisons used chi-square for discrete data and independent sample T-tests for continuous data. Correlations were assessed with the Pearson or Spearman correlation coefficient as required by data distribution. To explore the relationship between measures of mental health, QOL and their potential predictors we constructed a set of five multivariate linear regression models, one each for the dependent variables Kessler-10, NDDIE, HADS-A, EQ-5D-5L and EQ-VAS. The independent variables for all models included age, sex, duration of epilepsy, number of ASMs used, geographic displacement, exacerbation of seizures after the war, severity of epilepsy, difficulties accessing ASMs, need for mental health support, difficulties accessing mental health support, and an interaction term with need for mental health support and difficulties accessing mental health support. A p-value of 0.05 was set for all inferential statistics. Multicollinearity was assessed with variance inflation factor measures.

## **Results**

A total of 305 participants completed the survey. The mean age was 38 (SD 12) years, and 123 (40%) were female. Of 100 patients (44%) who had to changed residence because of the war, 89 (29%) relocated within Ukraine, and 11(3%) outside Ukraine (Table 1).

**Table 1. Demographic and clinical variables**

Variable			Mean	SD	Median	Count	%
Demographics							
Age (years)			38	12	37		
Gender	Female					123	40.30%
	Male					180	59.00%
	Prefer not to disclose					2	0.70%
Change of residence because of war	No					203	66.60%
	Yes	Within Ukraine				89	29.18%
		Outside Ukraine				11	3.16%
Clinical course of epilepsy							
Duration of epilepsy (years)			14.96	11.55	11.5		
Seizures before war	No					78	25.60%
	Yes					227	74.40%
Increase in seizures after start of war	No					155	50.80%
	Yes					150	49.20%
Number of ASMs	Monotherapy					179	61.70%
	Polytherapy					111	38.30%
Severity of epilepsy now			3	1	3		
Categories of severity	Not at all severe					66	21.60%
	A little severe					58	19.00%

	Somewhat severe	46	15.10%
	Moderately severe	86	28.20%
	Quite severe	42	13.80%
	Very severe	4	1.30%
	Extremely severe	3	1.00%

#### Access to care

Need mental healthcare	No	187	61.30%
since start of war	Yes	118	38.70%
Problems getting mental	No	170	55.74%
healthcare since the war	Yes	135	44.25%
Problems getting routine	No	231	75.74%
medical care since the war	Yes	74	24.26%
Problems getting <b>both</b>	No	276	90.5%
routine care and mental	Yes	29	9.51%
health care			
Problems accessing ASMs	No	199	65.20%
during war	Yes	106	34.80%

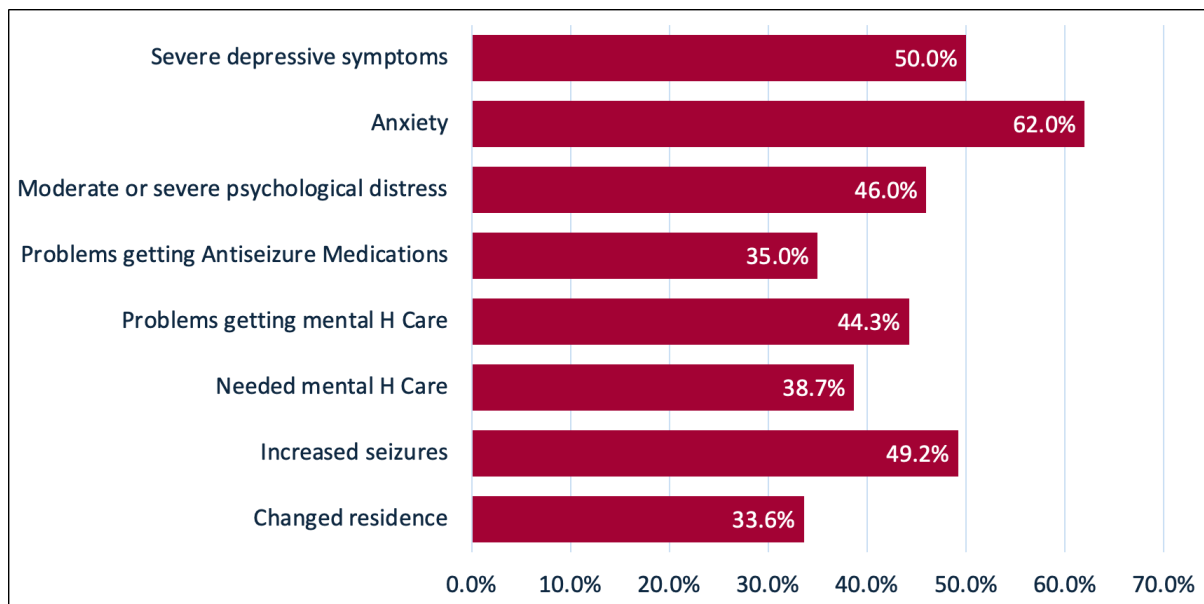
#### Mental health measures

NDDIE - Depressive	13	4	13
symptoms			
K-10- Psychological	22	8	21
distress			

K10 Score categories	Likely to be well	125	41.00%
	Mild distress	72	23.60%

	Moderate distress				43	14.10%
	Severe distress				65	21.30%
HADS-A - Anxiety		9	4	9		
HADS-A categories	Normal				116	38.00%
	Mild				81	26.60%
	Moderate or severe				108	35.40%
Quality of life	EQ-5D-5L	0.84	0.15	0.86		
	EQ-VAS	64	19	65		

The mean duration of epilepsy was 14.96 years (11.55 SD). Of 227 (74%) patients who reported having active epilepsy (i.e., seizures within one year), 52% reported an increase in seizures after the start of the war (Figure 1). Among 78 patients who reported having no seizures during one year before the war, 42% also reported an increase in seizures. Difficulties accessing medical care was reported by 24%, and 35% reported difficulties accessing ASMs at some point during the war (Figure 1). Patients used 11 different ASMs, most frequently carbamazepine (37.4%), valproate (33.1%), lamotrigine (24.3%) and levetiracetam (20.7%); 38% of patients required polytherapy. There was a statistically significant relationship between changing residence since the beginning of the war and having difficulty accessing anti-seizure medications (chi square=5.926, df=1, p=0.014).

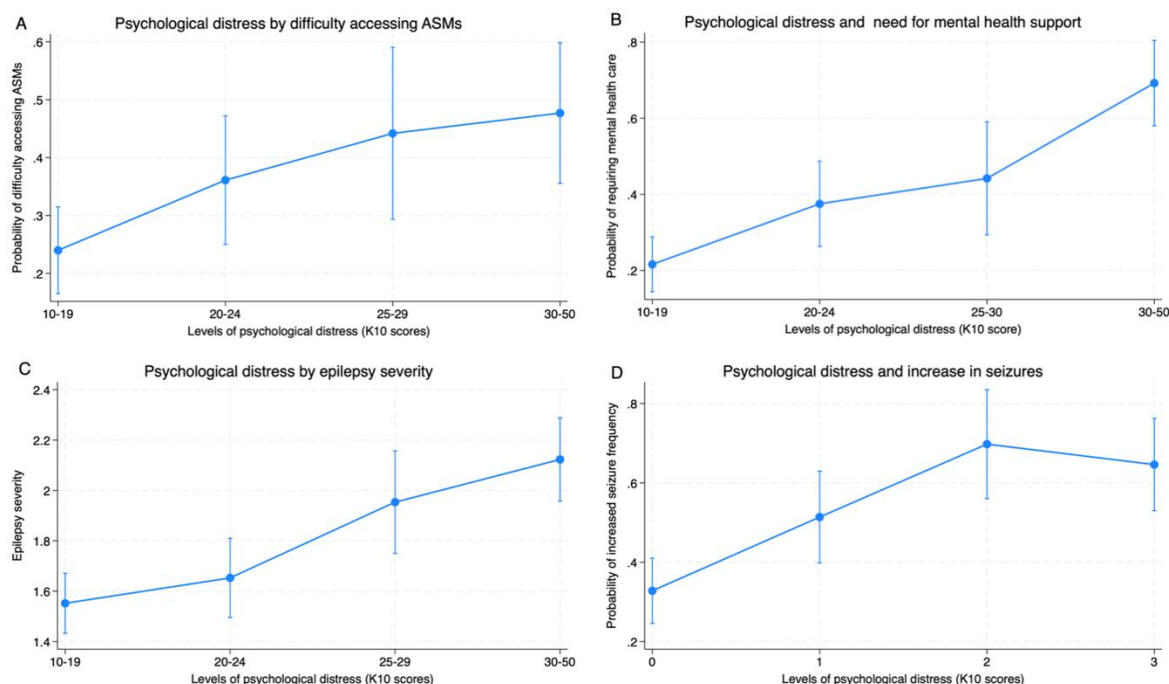


**Figure 1. Proportion of patients with adverse experiences during the war**

The median rating of epilepsy severity (GASE scale) was 3 (somewhat severe) and 59 % rated their severity as somewhat severe or worse. Mean (SD) QOL scores were 0.84 (0.15) for EQ-5D-5L index, and 64 (19) for the EQ-VAS. EQ-5D 5L scores were lowest among those aged 45-54, and there was a non-significant trend towards lower scores among females compared to males.

The average score for psychological distress (K10) was 22.45 (SD 8.06) suggesting moderate distress. Moderate or severe levels of psychological distress (scores  $\geq 25$ ) occurred in 46% of patients (Figure 1). Between group differences that trended toward statistical significance included higher distress in females than males (mean 23.33 vs 21.78,  $p=0.09$ ); and highest levels of distress in those over 65 years compared to those aged 18-24 years (mean 26.83 vs 19.08). In univariate analyses, there was a graded relationship between increasing levels of psychological distress and the probability of

having difficulties accessing ASMs ( $p=0.005$ ), increased seizure frequency ( $p<0.001$ ), need for mental health care ( $p<0.001$ ), and progressively higher levels of epilepsy severity ( $p<0.001$ ) (Figure 2). Mild or moderate anxiety (HADS-A  $>7$ ) was reported by 62% of patients, and it was more common in females than males (58% vs 49%). NDDIE scores indicating depression ( $>13$ ) were present in 50% of patients, with similar proportions in females (52%) and males (48%) (Figure 1). There was a gradient of predicted levels of psychological distress and the probability of having more severe epilepsy, requiring mental health, increase in seizure frequency, or difficulty accessing ASMs, with worsening scores in the K10 as these probabilities increased (Figure 2).



**Figure 2.** Levels of psychological distress and increasing predicted probabilities of having A) difficulty accessing ASMs; B) requiring mental healthcare; C) increasing levels of epilepsy severity; D) worsening seizure frequency

The results of multivariate regression analyses are presented in Table 2. There was no evidence of multicollinearity as demonstrated by variance inflation factor values <2 across all independent variables in all models. The predictive value of all models was medium to large, with adjusted R-squared values ranging from 0.25 to 0.33, except for the EQ-5D-5L model, which had a low predictive value (R-squared=0.03). Predictors of mental health were similar for all three measures (K10, NDDIE, HADS-A); female patients, those needing mental health care, and those with more severe epilepsy had significantly poorer mental health, including psychological distress, and more severe depressive and anxiety symptoms. Increased seizures also correlated with higher distress and anxiety. Epilepsy severity emerged as a prominent predictor (high  $\beta$  coefficients) for all measures of mental health and also QOL as measured by EQ-5D-5L and EQ-VAS. Other predictors of QOL included increase in seizures, female gender and, for EQ-5D-5L, increasing age.

TABLE 2. Multivariate linear regression models for QOL and mental health

Measure and predictors	Coefficient	95%CI	$\beta$ Coefficient	<i>p</i>
<b>K-10 (10 to 50)</b>				
Sex male	-2.42	2.98, 7.46	-0.15	0.005
Need mental health care	5.22	2.98, 7.46	0.32	<0.001
Increased seizures	1.96	0.22, 3.69	0.12	0.027
Epilepsy severity	1.60	0.99, 2.22	0.30	<0.001
<i>Adjusted R<sup>2</sup> = 0.29</i>				

**EQ-5D-5L (-0.59 to 1.0)**

Age (years)	-0.003	-0.004, -0.001	-0.211	0.002
Sex male	0.05	0.01, 0.08	0.16	0.008
Epilepsy severity	-0.02	-0.03, -0.01	-0.20	0.003

*Adjusted R<sup>2</sup> = 0.09*

**EQ-VAS (0 to 100)**

Epilepsy severity	-5.61	-7.01, -4.20	-0.44	<0.001
Increased seizures	-4.7-	-8.66, -0.75	-0.13	0.020

*Adjusted R<sup>2</sup> = 0.33*

**NDDIE (6 to 24)**

Sex Male	-0.89	-1.74, -0.04	-0.11	0.039
Duration of epilepsy (years)	0.04	0.00, 0.08	0.13	0.035
Need mental health care	1.55	0.43, 2.67	0.19	0.007
Epilepsy severity	0.80	0.49, 1.11	0.30	<0.001

*Adjusted R<sup>2</sup> = 0.25*

**HADS-A (0 to 21)**

Sex male	-1.50	-2.40, -0.61	-0.18	0.001
Need mental health care	2.07	0.88, 3.26	0.24	0.001
Increased seizures	1.03	0.10, 1.95	0.12	0.029
Epilepsy severity	0.84	0.51, 1.16	0.29	<0.001



*Adjusted R<sup>2</sup> = 0.28*

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Note for table 2: Models for each dependent variable (K-10, EQ-5D-5L, EQ-VAS, NDDIE, HADS-A) included the same independent variables: age, sex, duration of epilepsy, number of ASMs used, internal or external displacement, increased seizures after the war, severity of epilepsy, difficulties accessing ASMs, need for mental healthcare, difficulties accessing mental health care, and interaction between need for mental healthcare and difficulties accessing mental healthcare.

## **Discussion**

Our evaluation of self-reported mental health and QOL measures in adults with epilepsy, one year into the war in Ukraine, underscores the significant burden faced by this vulnerable population. Only a few physical consequences of the war were explored, among them geographic displacement, which occurred in 44% of patients and was significantly associated with difficulty accessing ASMs. Alongside physical consequences, the war has caused restricted access to routine medical care, mental health support and ASMs. This, coupled with heightened seizure activity, has had detrimental effects on mental health and QOL. Seizure exacerbation occurred both in previously seizure-free patients, as well as in those with more recent seizures, underscoring the heightened susceptibility of epilepsy to crisis situations.

A large proportion of patients suffered from high levels of anxiety, depressive symptoms, and psychological distress, and we aimed to find factors that most strongly predicted

poor mental health. Several associations found in univariate analyses, such as the relationship between restricted access to ASMs and increased psychological distress, lost predictive ability once incorporated in multivariate models. In these models, a few variables consistently emerged as the strongest predictors of mental health, namely, female sex, seizure exacerbation, needing mental health support, and most prominently, the patients' rating of the severity of epilepsy (GASE scale). Epilepsy severity consistently exhibited the highest or second highest  $\beta$  coefficient across all models. Conceivably, its high explanatory power lies in its ability to globally encapsulate the myriad effects of the war, ultimately leading to heightened disease severity. On the other hand, we were unable to demonstrate an association with clinical variables such as epilepsy duration, age, number of ASMs used, and difficulties accessing health care. It is plausible that the impact of these clinical factors was more completely captured by the global measures of seizure severity, increased seizures, and need for mental health support.

The predictors of QOL differed from those for mental health. Only seizure increase, epilepsy severity and sex retained predictive power. Our finding that the need for mental health support is not a significant predictor of quality of life (QOL) underscores the distinction between mental health and QOL. This suggests that QOL captures a broader spectrum of well-being, encompassing aspects beyond just mental health problems such as psychological distress, depressive symptoms, and anxiety. Our analysis revealed a surprisingly low explanatory power to predict QOL as measured by the EQ-5D-5L in this context ( $R^2 = 0.03$ ). This is noteworthy because more severe depressive symptoms, which were present in a large segment of the population, are a well-established factor influencing QOL<sup>2</sup>, and additionally, the EQ-5D-5L itself includes a

mood assessment item. This suggests that during crisis situations like the war in Ukraine, factors beyond traditional mental health measures, including insecurity, threats to physical safety, disease exacerbation, and access to healthcare, may have a stronger impact on QOL, as measured by this instrument. Female sex emerged as a predictor of poor function for all mental health measures and QOL, except in the EQ-VAS measure. However, it did not rank among the top predictors (lower beta coefficients) for any of the outcomes.

Our study has limitations. Addressing research inquiries that necessitate patient involvement becomes notably arduous amidst the backdrop of war. Population displacement, disrupted transportation, and communication infrastructure, coupled with constrained access to healthcare services, impede the availability of patient responses. As a result, the granularity of collected data is limited. Furthermore, the population included in the survey was limited to those patients that could access health centres during a time of war. It was entirely unfeasible to apply sampling methods that insure low risk of selection bias (e.g., through random or probabilistic population sampling). This risk of selection bias may impact patient representativeness. Nonetheless, factors such as patient sex, epilepsy duration, and the type and number of anti-seizure medications (ASMs) align with characteristics typically observed in the chronic epilepsy population receiving regular care, which may help assuage concerns about severe selection bias.

Identifying individuals at high risk for adverse mental health outcomes is a crucial clinical responsibility requiring proactive intervention. However, our study uncovered significant challenges in accessing mental health care during times of conflict, limiting our ability to

intervene effectively. Despite these obstacles, pinpointing and flagging patients at risk represents a critical first step in meeting the mental health needs of this vulnerable population. To address this, we identified validated cut-off scores for various instruments indicating heightened risk or severe psychological distress. Whenever a patient's scores surpassed these thresholds, the attending clinician received immediate notifications, containing the patient's ID number, which enabled the clinician to promptly seek available resources to address the patient's mental health concerns. According to personal communication from colleagues within the Ukrainian League Against Epilepsy, individuals with severe mental disorders were typically evacuated within Ukraine and provided with medical care in specialized facilities that remained unscathed by the conflict.

Lastly, it is important to point out that specific variables may help identify PWE with a heightened risk for mental health problems during conflicts. These include women, seizure exacerbation, more severe epilepsy, and the need for mental health support. Allocating resources to address these populations specifically may help alleviate the tremendous burden imposed by these crises.

## **Conclusions**

Seizures worsened during the war in half of the patients, including those with well-controlled epilepsy. Difficulties accessing health care and antiseizure medications occurred in a quarter to a third of PWE and was worse among those who were displaced. From 40% to 60% of the patients reported clinically significant ratings of depressive symptoms, anxiety, and psychological distress, and 59% rated their epilepsy as

somewhat severe or worse. Statistically significant predictors of psychological distress, anxiety and more severe depressive symptoms included female gender, more severe epilepsy, increased seizures during the war, and requiring mental health support. Identification of patients at high risk can guide resource allocation for prevention and treatment.

**We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.**

**Author contribution:**

All authors contributed to the conceptualization and design of the study, and all reviewed and edited the manuscript. A Dubenko was responsible for distribution of the survey and data collection. Rinaldo Morelli and S Wiebe performed analyses and drafted the manuscript. All authors approved the final version of the manuscript.

A Dubenko: ORCID: [0000-0001-9626-3638](#)  
V Kharytonov: ORCID: [0000-0002-9875-7209](#)  
J H Cross: ORCID: 0000-0002-1061-9099  
R Morelli: ORCID: 0009-0007-8911-7633  
R Michaelis ORICD: 0000-0002-2577-0824  
S Wiebe: ORCID: 0000-0002-1061-9099

**Conflict declaration**

AD has no conflict of interest related to this study.

VK has no conflict of interest related to this study.

JHC has participated in clinical trials sponsored by Zogenix/UCB Pharma, GW Pharma/Jazz Pharmaceuticals, Marinius, Stoke Therapeutics and Ultragenyx, and sat on advisory boards

for Nutricia, Biocodex, UCB, Stoke Therapeutics, Takeda all with remuneration all to department and unrelated to this work

JH has no conflict of interest related to this study

RMo has not conflict of interest related to this study

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