

Indonesia League Against Epilepsy 2021-2022 Report

CHAPTER OFFICERS

Aris Catur Bintoro, President
Machlusil Husna, Secretary
Fitri Octaviana, Treasurer

Officer Election Date: October 2019



ACTIVITIES AND ACCOMPLISHMENTS

- Epilepsy education to the public
 - Spread through television/radio/newspaper broadcasts: addressing epilepsy during Purple Day and International Epilepsy Day from 14 epilepsy centers in Indonesia
 - Perceptions, attitudes, and behaviors in families and people with epilepsy
 - Counseling on epilepsy and seizures and how to help our loved one with epilepsy.
- Workshop/teaching course: EEG and epilepsy
- Symposium for neurologists:
 - Epilepsy and comorbidities
 - Antiseizure medication
 - Optimize The Role of Perampanel in The Treatment Strategy for Epilepsy
 - Role of Levetiracetam as Adjunctive OAE in Partial Onset Epilepsy
 - Potential mechanism and rational treatment of epilepsy and COVID-19
- Symposium for general practice: Epilepsy education through television, radio, newspapers
- ASEPA Manado Virtual Epilepsy Summer Course, 14-15 August 2021
- Letter to Neurology Association Indonesia: Guidelines for Administering the COVID-19 Vaccine to Epilepsy Patients, January 2021
- Letter to the Constitutional Court: Expert Statement Letter from the ILAE Chapter / Indonesia Epilepsy Study group to the Constitutional Court Judge at the trial of the Law lawsuit regarding the unavailability of Medical Marijuana as an anti-epileptic drug in Indonesia, 13 September 2021
- Letters and meetings with the Food and Drug Supervisory Agency: Proposals for anti-epileptic drugs for the Indonesian National Medicine Formulary for June 2021
- Letter to ILAE Asia & Oceania: Letter of recommendation to Dr. Anna Marita Gelgel in selection of ILAE Asia & Oceania committee member, 18 March 2021
- Launching a book: 'Epilepsy: Myths & Facts', Indonesian Epilepsy Foundation, 2022
- 13th AOEC: Support for ILAE Indonesian Chapter members as speakers for the 13th APEC Japan (Dr. Fitri, Dr. Aris, Dr. Suryani, Dr. Wardah, Dr. Diah), June 2021

- 12th and 13th AOEC/AOEA nomination from Indonesia (Professor Dr. Harsono April 2021) (Dr. Dede Gunawan November 2022)



Purple Day (Family Gathering and Sharing Session), Wahidin Sudirohusodo Hospital, Makassar, 27 March 2022



International Epilepsy Day

ROLLING IN THE morning!

Prof. dr. Zainal Muttaqin, PhD, SpBS(K)
(Dokter Spesialis Bedah Saraf)

dr. Aris Catur Bintoro SpS(K)
(Dokter Spesialis Saraf)

Tema: Ganja Medis Sebagai Obat Epilepsi?

JUMAT, 8 JULI 2022 | JAM 08.00 - 09.00 WIB

Medical Cannabis as a Drug for Epilepsy Education from radio

INTERNATIONAL LEAGUE AGAINST EPILEPSY **ILAE** Commission on Asian Oceanian Affairs

IDI ACCREDITED

In collaboration with Asian Epilepsy Academy, proudly presents

ASEPA-MANADO VIRTUAL EPILEPSY SUMMER COURSE

FIRST ANNOUNCEMENT

Neurologists practicing in the eastern part of Indonesia or remote areas will be prioritized

MANADO | AUGUST 14-15, 2021

Virtual Zoom Meeting
Email: asepa.manado.epilepsycourse@gmail.com
Registration Link: <https://bit.ly/3fJH4rl>

Join Us IDR 200.000

LIMITED SEAT
60 Persons

Contact Persons:
KENNYTHA (081386951238)
STELLA (081315720084)

Certificate will be issued to all participants with at least 80% attendance

ASEPA Manado Virtual Epilepsy Summer Course, Manado International League Against Epilepsy

Bali Medical Journal (Bali Med) 2021, Volume 10, Number 2: 521-525
P-ISSN 2089-1180, E-ISSN 2302-2914

Description of depression in people with epilepsy in Aceh

Nova Dian Lestari^{1,2*}, Nirwana Lazuardi Sary¹, Arina Khairu Ummah¹, Zulkarnain¹, Nur Astini^{1,3}

ABSTRACT

Background: Depression is the most common comorbid in people with epilepsy (PWE). Detection of depression in PWE is not a routine examination at a neurology clinic because it takes a long time. The education of Aceh people regarding epilepsy is still limited, leading to discrimination and stigma in society. It is not easy to carry out examinations, and the diagnosis is often overlooked. The objective of this study was to screen and to describe the characteristics of depression in PWE in Aceh.

Method: This study was a descriptive observational study with the total respondents involved 41 PWEs. Detection of depression in PWE was conducted using the Neurological Disorders Depression Inventory for Epilepsy (NDDE-E), a valid, reliable, shorter and more straightforward instrument test. The sample was determined using the probability sampling method with a simple random sampling technique.

Results: Our results found that 39% of respondents experienced depression, with the most NDDE-E scores ranged between 11-15, with a percentage of 41.5%. Out of total, 57.1% of the depression occurred in women and those who aged between 12-25 years old were more frequent to experience depression. Depression was more frequent among those who had no formal education (66.7%).

Conclusion: Depression in PWE in Aceh tends to occur in women, those with no education and those who worked as labor or farmer.

Keywords: Aceh, depression, epilepsy, NDDE-E, people with epilepsy

Cite This Article: Lestari, N.D., Sary, N.W., Ummah, A.K., Zulkarnain, A., Astini, N. 2021. Description of depression in people with epilepsy in Aceh. Bali Medical Journal 10(2): 521-525. DOI: 10.15562/bali.v10i2.2189

Received: 2021-04-17
Accepted: 2021-06-19
Published: 2021-06-20

INTRODUCTION

Epilepsy is a brain disorder characterized by a tendency to induce epileptic seizures with neurobiological, cognitive, psychological, and social consequences. Epilepsy accounts for a significant proportion of 0.5% of the world's disease burden. As many as 80% of people with epilepsy (PWE) live in low- and middle-income countries.¹⁻³ Based on data from the Central Statistics Agency of Aceh Province in 2016, epilepsy ranked third in mental health cases in Aceh after schizophrenia and acute psychotic disorders.⁴

Epilepsy can occur at any age, gender, and race and causes mortality and early death.⁵ The risk of premature death in people with epilepsy can occur up to three times higher than the general population, with the highest early death rates in low- and middle-income countries and rural areas.⁶ Proper treatment and diagnosis can prevent these mortality rates. Two

factors cause it, the stigma factor and the natural factor of the brain. Self-stigma arises from the distrust of having to suffer from epilepsy from the sufferer himself. Social stigma by society against PWE also frequently occurs in several countries, such as discrimination, humiliation, fear, and interaction barriers. Another contributing factor is a natural brain factor related to the imbalance of brain chemicals in PWE, which influences depression, such as low serotonin levels in the brain.⁷ Several PET studies have found that serotonin receptors' binding is reduced in various PWE brain areas. The site with reduced serotonin receptor binding potential is ipsilateral with a reorganizing focus, particularly during seizure onset and areas of seizure propagation. These factors have a serious impact on PWE, which causes sufferers to experience decreased quality of life, depression, a worse prognosis, and multiple suicidal impulses.^{8,9}

Depression is a comorbid symptom

that often occurs in epileptic patients.¹⁰ From a psychological perspective, the terms depression and anxiety in epilepsy are expressed as an increased emotional response to seizures' unpredictable nature and activity restriction.¹¹ In the context of the two-way relationship between epilepsy and depression, not only is PWE at greater risk of developing depressive comorbidities, but patients with depression had a four to seven times higher risk of developing epilepsy.¹²⁻¹⁴ Depressive disorder ranked first in three decades from 1990 to 2017. Several studies explain that cases of depression in PWE worldwide are recorded relatively high at 9.5-85 percent,¹⁵ and according to the Institute of Health Metrics and Evaluation (IHME), depression is a factor that contributes to a large number of suicides in Indonesia.¹⁶ The results of primary health research (Biokendal) 2018 by the Indonesian Ministry of Health showed the prevalence of depression in the total

Open access: www.balimedicaljournal.org 521
Description of Depression in People with Epilepsy in Aceh



Attitudes toward epilepsy in Indonesia
 Gunadharna Suryani^{a,*}, Seilly Yunita Jehosua^b, Khosama Herlyani^b, Chia Zhi-jien^c,
 Lim Kheng-Seang^d

^aDepartment of Neurology, Faculty of Medicine, University of Padjadjaran/Hassan Sadikin Hospital, Bandung, Indonesia
^bDepartment of Neurology, Faculty of Medicine, University of Sam Ratulangi/Prof. Dr. Kandou Hospital, Manado, Indonesia
^cDivision of Neurology, Department of Medicine, Faculty of Medicine, University of Malaya, Malaysia

ARTICLE INFO

Article history:
 Received 23 March 2021
 Revised 25 July 2021
 Accepted 25 July 2021

Keywords:
 Epilepsy
 Attitudes
 Stigma
 Indonesia

ABSTRACT

Background: Indonesia is the largest island country in the world with diverse ethnicity and cultural backgrounds. This study aimed to understand the variation in attitudes toward epilepsy among the Javanese, Sundanese, and the Minahasan ethnic groups in Indonesia.
Method: This study recruited Sundanese from Tasikmalaya and Minahasan from Manado using the Indonesian Public Attitudes Toward Epilepsy (PATE) scale. The results were compared to the Javanese and Malaysian data in previous studies.
Result: A total of 200 respondents, 100 from each ethnic group were recruited, with a mean age of 38.51 years. They were predominantly females (54) and had secondary education level or lower (58.67%). The Javanese had a higher total mean score, indicating poorer attitudes toward epilepsy, as compared to the Minahasan and Sundanese groups. These differences were noted in the personal domain, but not the general domain. There were no significant differences in the mean scores in both personal and general domains between the Minahasan, Sundanese, and Malaysian populations. Subanalysis on the aspects of life showed that the Javanese had a significantly higher score in the aspects of education, marital relationship, and employment.
Conclusion: The attitudes toward epilepsy were similar between the Indonesian (Sundanese and the Minahasan) and Malaysian, except the Javanese with poorer attitude. These differences could be socio-economically or culturally related.

1. Introduction

Epilepsy was known to cause significant psychosocial consequences in most aspects of life including employment, social interactions, family relationships, and sporting activities, leading to poor quality of life [1]. These consequences might be due to impaired social cognitive skills or social stigma [1,2]. Seizures and epilepsy were often associated with sins, demonic possession, insanity, and considered contagious, especially in Asian countries [3]. Many Indonesian people consider epilepsy not as a disease but connected with mystic such as possessed by evil, and some of them still believed that it is contagious [4]. The prevalence of epilepsy in developing countries is usually higher than in developed countries. Over half of the 50 million people with epilepsy worldwide are estimated to live in Asia [3]. In Indonesia, new epilepsy cases were estimated to be 250,000/year [5]. Indonesia is the largest island country in the world with a pop-

ulation of 264 million, with diverse ethnicity and cultural backgrounds, which make it important to understand the variability and degree of the attitudes toward epilepsy in this country. Javanese (40%) is the largest ethnic group in Indonesia, followed by Sundanese (15%), Malays (13%), Sulawesians (13%), and others. However, they are distributed in different geographical locations, e.g., Javanese and Sundanese in Java island and Minahasan in North Sulawesi [6]. The Public Attitudes Toward Epilepsy (PATE) scale was first designed and applied in Malaysia to measure the public attitudes toward employment, education, social and marital relationship among people with epilepsy (PWE). The PATE scale divided attitudes toward epilepsy into general and personal dichotomy based on the requirement of long-term personal commitments [7–11]. The PATE scale was translated to Indonesian language and shown to be a validated and reliable translation for measuring PATE. Bahasa Indonesia (Indonesian language) has been adopted as the national language to facilitate communication and national unity, though there are many spoken languages in Indonesia [12]. This study aimed to determine the attitude toward epilepsy among the Javanese from Jakarta, Sundanese from Tasikmalaya, and Minahasan from Manado using the Indonesian PATE scale.

* Corresponding author.
 E-mail address: suryani@gmail.com (G. Suryani).

https://doi.org/10.1016/j.yebeh.2021.108244
 1523-5006/© 2021 Elsevier Inc. All rights reserved.

"Attitudes toward epilepsy in Indonesia", Elsevier 2021

965 | Indonesian neurologist understanding and experience in epilepsy care during covid-19 pandemic

Aris Catur Bintoro^a, Machlusi Husna^b, Herlyani Khosama^c, Fitri Octaviana^d, Suryani Gunadharna^e, Endang Kustiawati^f, Anna Marita Gelgel^g, Kurnia Kusumastuti^h, Astri Budikagantiⁱ
^aFaculty of Medicine, University of Diponegoro/Dr. Kariadi General Hospital, Semarang, Indonesia; ^bFaculty of Medicine, University of Brunei Darussalam/Sarif Al-Anwar General Hospital, Malang, Indonesia; ^cFaculty of Medicine, University of Sam Ratulangi/Prof. Dr. R. D. Kandou General Hospital, Manado, Indonesia; ^dFaculty of Medicine, Universitas Indonesia/Cipto Mangunkusumo General Hospital, Jakarta, Indonesia; ^eFaculty of Medicine, University of Padjadjaran/Dr. Hassan Sadikin General Hospital, Bandung, Indonesia; ^fFaculty of Medicine, University of Udayana/Sanglah General Hospital, Bali, Indonesia; ^gFaculty of Medicine, University of Airlangga/Dr. Soetomo General Hospital, Surabaya, Indonesia

Purpose: To gather information from Indonesian Neurologist understanding and experience about impact of Covid-19 pandemic on epilepsy care.
Method: Survey using ILAE's COVID-19 questionnaire for clinicians about impact of COVID-19 on epilepsy care, was conducted on June and November 2020 during Neurologist National webinars. All participants were Indonesian Neurologist. ILAE's COVID-19 questionnaire for clinicians consist of 4 open-ended and 2 closed-ended questions about their understanding, experience and research priorities.
Result: There were 381 participants. Most participants (75.33%) had sufficient understanding of how COVID-19 infection may present and affect seizure frequency and management in epilepsy. The top 3 urgent research priorities suggested from participants to cover current gap in clinical knowledge were COVID-19 treatment in epilepsy (32.5%), correlation between COVID-19 and epilepsy (24.7%), and association COVID-19 with heart disease (9.4%). In experience section, 71.9% had never experience nor reported about new onset epilepsy as a neurological presentation or outcome related to COVID-19. Concerning these matters, 23.9% considered important research in clinical neurophysiology, neuro-intensive care, psychiatry problems and encephalitis in COVID-19. Furthermore, 60.4% participant could not anticipate disruptions in epilepsy care and supply of antiepileptic drugs (AED). Participants were aware about changes in patient's mental health, psychosocial and epilepsy severity especially in nonadherence to AED (82.7%), anxiety (79.3%),

ABSTRACT

depression (77.9%). Sleep patterns changes, increased risk of seizure-related accidents, and discriminations were less expressed by patients and their families/partners; 67.7%, 59.8%, and 59.6%, respectively. Fewer problems reported in alcohol/substance abuse (36.8%), isolation (35.6%), and suicidality (30.9%).
Conclusions: Indonesian Neurologist had sufficient understanding about impact of Covid-19 pandemic on epilepsy care. They were aware of patient's psychiatric problems and nonadherence to AED, but could not anticipate any disruptions in epilepsy care and AED supply. COVID-19 treatment in epilepsy was considered as prior-

Epilepsia | 119

ity disorders in youth with epilepsy of 18.9% and for depression of 13.5%, our sample showed +33.4% of anxiety and +41.9% of depressive symptoms during COVID-19 pandemic.
Conclusions: Our sample showed very elevate rates of anxious depressive disorders during COVID-19 pandemic. These findings reveal that pediatric patients with epilepsy need urgent attention from government and clinicians as well as mental health protocols of screening and treatment during and after COVID-19 pandemic.

1143 | Impact of COVID pandemic on Ketogenic

"Indonesian neurologist understanding and experience in epilepsy care during COVID-19 pandemic"

Report submitted by Aris Catur Bintoro