

# ISSUES RELATED TO WOMEN WITH EPILEPSY IN LOW- AND MIDDLE- INCOME COUNTRIES

Akhtar Sherin<sup>1</sup>, Fouzia Gul<sup>2</sup>

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Epilepsy is the third major cause of global burden of neurological diseases after stroke and headache.<sup>1</sup> Out of 50 million people with epilepsy worldwide, about 80% are living in low- and middle-income countries (LMIC).<sup>2</sup> The magnitude of the problem in these countries is worsened by high treatment gap as over 75% of epilepsy patients in low-income countries and more than 50% in middle-income countries, are not receiving the required treatment.<sup>3</sup> Although epilepsy is relatively more common in males, gender variation in prevalence rates of subtypes of epilepsy has been reported.<sup>4,5</sup> Under-reporting of epilepsy in women due to various social reasons may contribute to lower prevalence of epilepsy in women.<sup>6</sup>

Although epilepsy has its own impact on both genders, being woman with epilepsy (WWE) has some special concerns and issues related to reproductive and social life.<sup>5,7</sup> The most critical issues in WWE in LMIC are the ignorance, stigma, myths and misconception of people about the nature and management of seizures and epilepsy.<sup>8</sup> Various fallacies about the cause and treatment of epilepsy in LMIC lead to adverse psychosocial outcome in WWE. Since ages, seizures were attributed to possession by evil spirits, witchcraft or divine curse. Until end of 20<sup>th</sup> century, epilepsy was judged as a lawful reason for marriage annulment in India.<sup>9</sup> Even after abolishing such laws, WWE in LMIC encounter the challenges of getting married, increased rate of

divorce, disturbed family relationships, difficulty in getting employment and awful stigma leading to psychological and emotional turmoil and lower quality of life.<sup>8,9</sup> World Health Organization (WHO), International League Against Epilepsy and International Bureau for Epilepsy have initiated the “Global Campaign against Epilepsy: Out of the Shadows” for public awareness and better understanding of epilepsy.<sup>10</sup> However, large scale, mass awareness campaigns on print, electronic and social media as well as integrating basic knowledge about epilepsy in curriculum at schools level are needed in changing the attitudes, perceptions and beliefs of people about epilepsy in LMIC.

WWE receiving antiepileptic drugs (AED) may face the challenges related to sexual dysfunction, infertility, issues in pregnancy, labor, lactation, contraception, hormonal imbalance leading to menstrual abnormalities/irregularities, menopause and bone health.<sup>11</sup> All these issues need specialized health care, which is lacking in primary and secondary settings of LMIC. General physicians in these countries are not properly trained to address these important issues. Lack of expertise in diagnosis and management of epilepsy is the major cause of inadequate management of epilepsy in these countries. According to WHO Neurology Atlas, there are 0.03 number of neurologist per 100,000 population for low-income countries as compared to 2.96 for high-income countries.<sup>12</sup> In India, there are only 1,100 neurologists

✉ Managing Editor Khyber Medical University Journal & Professor of Medicine, Khyber Medical University- Institute of Medical Sciences Kohat- Pakistan  
E mail: akhtarsherin@yahoo.com  
<sup>2</sup> Dean Medical Education & Research, Professor of Gynae/Obs, Khyber Medical University- Institute of Medical Sciences Kohat- Pakistan

for more than a billion population.<sup>13</sup> In Pakistan there is one neurologist for 1.4 million population and one neurologist for every 15200 patients of epilepsy.<sup>14</sup> Non-availability of specialist care in LMIC can be surmounted by arranging special training courses for general physicians on issues related to WWE. Liaison of professional societies of neurologists and gynecologists can be vital in addressing appropriate management of epilepsy in women.

Another important issue for WWE in LMIC is the high treatment gap. In India, treatment gap for epilepsy ranged from 22% for urban and 40-90% for rural population.<sup>3</sup> In Cambodia, treatment gap was observed in 65.8% cases.<sup>15</sup> Jia Hu et al showed no gender difference for treatment gap in epilepsy patients in rural china.<sup>16</sup> von Gaudecker JR did qualitative study on treatment gap in WWE and highlighted various barriers to treatment like financial constraints, stigma of epilepsy, non-availability and side-effects of drugs and dependence on family members in treatment.<sup>8</sup> Long term strategic plan to reduce the treatment gap in WWE in LMIC is direly needed and it can only be possible when all stake holders are actively involved by the respective governments in these countries.

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**CONFLICT OF INTEREST**

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**GRANT SUPPORT AND FINANCIAL DISCLOSURE**

NIL

KMUJ web address: [www.kmuj.kmu.edu.pk](http://www.kmuj.kmu.edu.pk)

Email address: [kmuj@kmu.edu.pk](mailto:kmuj@kmu.edu.pk)