Article published online: 2023-05-08

Knowledge, Risk Perception, and Reproductive Decision Making among Women with Epilepsy

Pallerla Srikanth[1] Mysore Narasimha Vranda[1] Priya Treesa Thomas[1] Kenchaiah Raghvendra[2]

[1] Department of Psychiatric Social Work, National Institute of Mental Health and Neuro-Sciences, Bengaluru, Karnataka, India
[2] Department of Neurology, National Institute of Mental Health and Neuro-Sciences, Bengaluru, Karnataka, India

Address for correspondence Mysore Narasimha Vranda, PhD, Department of Psychiatric Social Work, National Institute of Mental Health and Neuro-Sciences, Bengaluru 560029, Karnataka, India (e-mail: vrindamn@gmail.com; vrandamn@nimhans.ac.in).

Int J Ep 2022;8:21–27.

Abstract

Introduction Epilepsy is a neurological disorder that causes neurobiological, cognitive, and psychosocial consequences. Such impairments lead to substantial social influence on women across their life cycle stages, mostly connected with stigma, the severity of illness, quality of life, and other psychosocial issues in adding to reproductive decision-making associated to risk perception. This study aimed to assess the knowledge, risk perception, and reproductive decision-making factors among women with epilepsy.

Materials and Methods A cross-sectional descriptive study was carried out to assess the knowledge, risk perception, and reproductive decision-making factors among women with epilepsy. A semistructured questionnaire was prepared to collect the sociodemographic and clinical characteristics of 49 women who sought treatment for epilepsy from a national tertiary referral care center for neuropsychiatry in South India. The researcher developed a 24-item questionnaire, including three open-ended questions to assess the knowledge about reproductive health issues and epilepsy.

Results The participants' mean age was 24.67 ± 3.72, where 51% had secondary education, 63.3% were married, and 46.9% were homemakers. Women with epilepsy have reported lower knowledge about the illness and about the pregnancy, childbearing practices, breastfeeding, and epilepsy-related factors. Content analysis of responses to open-ended questions brought out the presence of marriage-related concerns, epilepsy and pregnancy, misconceptions about the pregnancy outcomes, and general misconceptions about the illness factors that play a role in reproductive decision-making among women living with epilepsy.

Conclusion The study reveals that women with poor knowledge about epilepsy and pregnancy have difficulty in reproductive decision-making, thereby increasing risk perception of childbearing. This places interest on the necessity for health care professionals to address the above psychosocial problems as part of their intervention plan.

Keywords
- knowledge
- reproductive decision making
- risk perception
- women with epilepsy

article published online
May 8, 2023

DOI https://doi.org/10.1055/s-0043-1768584.
ISSN 2213-6320.

© 2023. Indian Epilepsy Society. All rights reserved.
This is an open access article published by Thieme under the terms of the Creative Commons Attribution-NonDerivative-NonCommercial-License, permitting copying and reproduction so long as the original work is given appropriate credit. Contents may not be used for commercial purposes, or adapted, remixed, transformed or built upon. (https://creativecommons.org/licenses/by-nc-nd/4.0/)

Thieme Medical and Scientific Publishers Pvt. Ltd., A-12, 2nd Floor, Sector 2, Noida-201301 UP, India

Introduction

Epilepsy is the second utmost common encountered neurological condition that enacts a significant burden on persons with epilepsy (PwE), their family caregivers, and health care systems.[1] The recent data in India estimates that the overall prevalence of epilepsy is 3.0 to 11.9 per 1,000 population and incidence is 0.2 to 0.6 per 1,000 populations per year.[2] It was assessed that there are about 2.73 million women with epilepsy (WwE) in this country, with 52% of them fit in to the reproductive age groups of 15 to 49 years.[3] Although epilepsy is a controllable disorder, the lack of availability and accessibility of neurological treatment, especially in rural India, has a significant impact on the treatment of outcomes.[4] The subpopulation of WwE have encounters and problems throughout their life span due to the epilepsy and antiepileptic medications. Antiepileptic medications affect hormonal changes and functions, affecting sexual and reproductive health.[5] Studies have established that WwE who are of childbearing age have different information and treatment due to the impact of epilepsy and antiepileptic medications than men.[5,6]

The sexual and reproductive need of WwE is different from a man. In specific, in females, epilepsy affects sexual development, sexuality, menstruation, fertility, pregnancy, breastfeeding, mother–baby relationship, and menopause in ways exclusive to their sex.[7] In India, due to the fear of social stigma and breakdown of marriage negotiations, it was found that more than half of WwE and their families conceal their history of epilepsy before their wedding.[8] Before reaching 22 years of age the average Indian woman bears her first child, and has little control over her own fertility and reproductive health. Despite conducting education and awareness campaigns stigmatization of PwE and having poor knowledge about the epilepsy are still prevalent in the Indian society.[9] Majority of India's population believes that epilepsy hinders normal education, marriage, and employment.[10] There is a dearth of literature related to study the risk perception and reproductive decision-making among WwE from the Indian background. Hence, this research aimed to know women's knowledge, risk perception, and reproductive decision-making among WwE who are of childbearing age.

Materials and Methods

The current research was a cross-sectional descriptive study. WwE seeking treatment for epilepsy from the inpatient and outpatient services of the department of neurology at tertiary care super speciality hospital located in South India were considered for the study.

A prospective sample of 49 WwE was selected using the following inclusion and exclusion criteria for the research consecutively. Inclusion criteria were: (1) female patients with the diagnosis of epilepsy between the age group of 18 to 35 years, (2) female patients who with the diagnosis of epilepsy by neurologists and on antiepileptic medications based on the International League Against Epilepsy criteria version 2017[11] diagnostic criteria, (3) those patients who speak Kannada, English, Telugu, and Hindi, and (4) given informed consent. Exclusion criteria were female patients with other comorbidities like major psychiatric illness and major neurological illness other than epilepsy. The study was conducted from December 2018 to February 2019.

Ethical statement: Ethical clearance for the research was obtained from the Institute Human Behavioural and Ethics Committee.

Data Collection

Measures of Data Collections

Semistructured questionnaire: The researchers developed a semistructured questionnaire to capture the WwE sociodemographic details and clinical profile.

Knowledge about reproductive health issues and epilepsy: The researcher prepared a questionnaire consisting of 24 items, which assess the knowledge about epilepsy, and marriage, sexuality, pregnancy, childbearing, and breastfeeding concerns among WwE. The responses for each item are "agree," "disagree," and "unsure" on a three-point Likert scale. The questionnaire also has three open-ended questions about knowledge about epilepsy, concerns about impact of antiepileptic drugs (AEDs) on pregnancy and also in controlling seizures and their major concerns about planning for pregnancy while on AEDs. The questionnaire was validated by experts working in the field of epilepsy. The questionnaire was pilot tested and modifications were made for main data collection. The subjects were informed about the research and sought the informed consent. All the subjects were reminded that they would stop or pause the interview or withdraw from the study at any moment without giving any reason. The confirmation of willingness to be part of this research was sought from all the WwE using the written consent. The hospital's interview/counseling room was used for the interview process and all the WwE were guaranteed of confidentiality.

Data Analysis

The data gathered using the questionnaire was checked, coded, and entered in MS-Excel, then into a computer-based statistical analysis. SPSS version 14.0 was used for the data processing. Content analysis was done for the responses to the open-ended questions.

Results

Sociodemographic Profile

The age group of WwE ranged from 18 to 35 years. Majority ($n = 31$, 63.3%) were married, $n = 37$ (75.5%) were educated, and $n = 23$ (46.9%) of the participants were homemakers. Among the married women, 27 participants have children, $n = 35$ (71.4%) had one child, and $n = 14$ (28.6%) had two children. Regarding the type of epilepsy among all the participants, 55.1% had generalized tonic-clonic seizures, whereas $n = 13$ (26.5%) had focal seizures, and $n = 9$ (18.4%) had unclassified seizures, while $n = 24$ (49.0%) had

 © 2023. Indian Epilepsy Society. All rights reserved.

5 to 10 years of duration of illness. Other sociodemographic and clinical profile of the WwE have already been published elsewhere.[12]

Quantitative Data Findings

Knowledge about Reproductive Health Issues and Epilepsy

Nearly one-fourth ($n = 11$, 22.4%) of the participants were unsure that epilepsy is either a genetic or hereditary disease. More than half ($n = 27$, 55.1%) of the participants have disagreed that epilepsy is an incurable disorder. Eighteen (36.7%) participants were unsure if seizures can be treated with drugs. A significant majority ($n = 46$, 93.9%) of the participants agreed that WwE should disclose her health state before marriage to the spouse/partner. Many ($n = 24$, 49.0%) of the participants were unsure that taking AEDs during pregnancy would control their seizure. A large number ($n = 39$, 79.6%) of the WwE worried about the risk of their children developing epilepsy (►**Table 1**).

Qualitative Data Findings

The results of content analysis revealed the presence of general misconceptions about epilepsy, marriage, and sexuality related concerns, and having epilepsy and impact of AEDs on pregnancy and its outcomes (►**Table 2**).

General Misconceptions about Epilepsy

Nine (18.4%) of the WwE have reported that epilepsy is a lifetime illness, $n = 8$ (16.3%) of them have reported epilepsy is a type of mental illness, and $n = 6$ (12.2%) of them have reported holding metal objects in hand will stop seizures.

The following quotes of WwE exemplify some of the above themes:

I believe that epilepsy is a lifetime illness, it will not be curable, whole life we have to take treatment, there is no end to it (G, Unmarried 22 years).

I have heard that holding the metal objects will stop the seizure attack…. even I have seen few incidents in my

Table 1 Knowledge about reproductive health issues and epilepsy

S.no	Item label	($N = 49$) Percentage (%)		
		Agree	Disagree	Unsure
1	I feel epilepsy is a genetic/hereditary disease	10 (20.4)	28 (57.1)	11 (22.4)
2	I feel epilepsy is due to mental retardation	3 (6.1)	25 (51.0)	21 (42.9)
3	I feel epilepsy is an incurable disorder	13 (26.5)	27 (55.1)	9 (18.4)
4	PwE become unconscious during every epileptic seizure.	47 (95.9)	1 (2.0)	1 (2.0)
5	PwE fall during every epileptic seizure	26 (53.1)	13 (26.5)	10 (20.4)
6	For most PwE, seizures can be treatable with drugs.	30 (61.2)	1 (2.0)	18 (36.7)
7	I feel WwE can marry	45 (91.8)	3 (6.1)	1 (2.0)
8	I feel WwE should marry a person who has epilepsy	0 (0)	48 (98.0)	1 (2.0)
9	I feel WwE should disclose her health state before marriage to the spouse/partner.	46 (93.9)	2 (4.1)	1 (2.0)
10	Marriage cures epilepsy	5 (10.2)	27 (55.1)	17 (34.7)
11	Marrying to a PwE is a sin	3 (6.1)	44 (89.8)	2 (4.1)
12	I feel WwE should avoid sexual intercourse for fear as it leads to pregnancy	6 (12.2)	29 (59.2)	14 (28.6)
13	Epilepsy can be transmitted through physical intimacy	2 (4.1)	24 (49.0)	23 (46.9)
14	Having a physical relationship will increase the frequency of epileptic attack	8 (16.3)	18 (36.7)	23 (46.9)
15	I feel WwE should consult a physician or neurologist to plan her pregnancy	43 (87.8)	0 (0)	6 (12.2)
16	Taking antiepileptic drugs during pregnancy will control the seizure	23 (46.9)	2 (4.1)	24 (49.0)
17	I feel WwE requires additional support/caring during pregnancy	49 (100)	0 (0)	0 (0)
18	I feel WwE cannot conceive	5 (10.2)	23 (46.9)	21 (42.9)
19	While taking epileptic medication, a woman cannot conceive	6 (12.2)	18 (36.7)	25 (51.0)
20	Epileptic medications will affect the fetus development	15 (30.6)	8 (16.3)	26 (53.1)
21	I feel WwE afraid of developing epilepsy to her children	39 (79.6)	9 (18.4)	1 (2.0)
22	I feel WwE cannot take care of a child	3 (6.1)	43 (87.8)	3 (6.1)
23	I feel WwE cannot breastfeed a child	11 (22.4)	21 (42.9)	17 (34.7)
24	Breastfeeding the child while on antiepileptic drugs harms the development of the child	11 (22.4)	15 (30.6)	23 (46.9)

Abbreviations: PwE, persons with epilepsy; WwE, women with epilepsy.

 © 2023. Indian Epilepsy Society. All rights reserved.

Table 2 Responses of women with regard epilepsy, marriage, sexual, and reproductive health issues

S.no	Theme	Some of the responses of WwE			Frequency ($N = 49$)
1	General misconceptions about the epilepsy	Epilepsy is a lifetime illness Epilepsy is a type of mental illness PwE can't take bath every day PwE can't go to work Holding metal objects in hand will stop seizures Epilepsy is a contagious disease PwE can't have normal intelligence Epilepsy can be treated by faith healers			9 (18.4) 8 (16.3) 7 (14.3) 7 (14.3) 6 (12.2) 4 (8.16) 3 (6.1) 2 (4.1)
2	Marriage and sexual related concerns	Unmarried WwE ($n = 18$)	• Sustaining marital relationship • Not able to discuss sexual issues with the doctor • Getting separated/divorce once the spouse or in-laws aware of epilepsy		6 (33.3) 4 (22.2) 2 (11.1)
		Married WwE ($n = 31$)	• Sustaining the support from spouse or in-laws • Martial negotiations • Sustaining marital relationship • Not able to discuss pregnancy issues with the doctor • Getting separated/divorce once the spouse or in-laws aware of epilepsy • Perceived believe AEDs shouldn't be consumed before intimacy		8 (25.8) 7 (22.5) 7 (22.5) 6 (19.3) 5 (16.1) 2 (6.45)
3	Epilepsy, taking AEDs, and pregnancy-related concerns	Unmarried WwE ($n = 18$)	• Problems associated with conceiving • Planning for pregnancy • Continuation of support from the spouse or in-laws to take AEDs • Seizures prevention during pregnancy • Side effects of AEDs during pregnancy		8 (44.4) 7 (38.8) 7 (38.8) 6 (33.3) 4 (22.2)
		Married WwE ($n = 31$)	With children ($n = 27$)	• Having AEDs during pregnancy • Side effects of AEDs • Planning for next child due to past experiences • Dose adjustments of AEDs • Anxiety related to delivery • Dealing criticism related to the continuation of taking AEDs	9 (33.3) 8 (29.6) 6 (22.2) 3 (11.1) 3 (11.1) 2 (7.40)
			Without children ($n = 4$)	• Having a seizure during delivery • Continuation of support from the spouse • Child-rearing practices • Pressure from family about planning for a pregnancy • Safety of AEDs • Side effects of AEDs during pregnancy • Seizure frequency during pregnancy • Planning for a pregnancy • Unwanted pregnancy	1 (25.0) 2 (50.0) 1 (25.0) 1 (25.0) 2 (50.0) 2 (50.0) 1 (25.0) 3 (75.0) 1 (25.0)
4	Concerns about the outcomes of the pregnancy	Preterm delivery Neonatal low birth weight Birth defects Child health will affect Child intelligence will be low Chances of miscarriage			8 (16.3) 5 (10.2) 4 (8.16) 4 (8.16) 2 (4.10) 1 (2.04)

Abbreviations: AEDs, antiepileptic drugs; PwE, persons with epilepsy; WwE, women with epilepsy.

village, where people kept a metal key chain during the seizure attack in the palm of the person who had a seizure attack (S, Married 24 years).

Marriage and Sexuality

WwE has reported many concerns related to marriage and sexuality, categorized into unmarried and married WwE concerns. Six (33.3%) of the participants have perceived concern about sustaining the marital relationship, and a small proportion ($n = 2$, 11.1%) of the participants were concerned about getting separated/divorce once the spouse or in-laws are aware of epilepsy. The majority ($n = 8$, 25.8%) of the married participants have perceived concern sustaining the support from the spouse or in-laws. Six (19.3%) of

 © 2023. Indian Epilepsy Society. All rights reserved.

them were concerned about not being able to discuss the sexual issues with the doctor. The following quotes of WwE demonstrate some of the above themes:

I am concerned that I cannot discuss sexual-related issues with the doctor, I have some doubts to clarify, but I felt uncomfortable discussing with the doctor (R, Unmarried, 21 years).

I am worried about the support from my spouse and in-laws when I become pregnant, will they be supporting me like before (P, Married, 28 years).

Epilepsy, Antiepileptic Medication, and Pregnancy

The concerns related to this were categorized into unmarried and married with and without children among WwE. Eight unmarried ($n = 8$, 44.4%) participants have perceived concern about problems associated with conceiving. Six (33.3%) of them worried about how to prevent seizure during pregnancy. Nine (33.3%) of the married women with children worried about continuing AEDs during pregnancy, while six (22.2%) participants were concerned about planning for the next child. The following quotes of WwE represent some of the above themes:

I am afraid about problems associated with conceiving, and I have a friend who is married and has epilepsy. She has shared her difficulties she has undergone during her pregnancy. (A, Unmarried, 23 years).

I am concerned about the side effects of medicines on fetus. I unsure of whether to stop or continue medicines? My in-law has been advising me to stop medications once I conceive. (J, Married, 26 years).

Outcomes of Pregnancy

Some of the WwE had concerns regarding preterm delivery ($n = 8$, 16.3%), five (10.2%) worried about neonatal low birth weight child, and one (2.04%) was concerned about the chances for miscarriage due to epilepsy.

The following quotes of WwE illustrate some of the above themes:

I am not planning for a second child both my husband and in-laws were critical towards me and haven't given support during my previous pregnancy. They used to blame me for the illness (C, Married with children 29 years).

I am afraid that whether my child will have any birth defects, every mother expects their child to be healthy; this thought keeps me worried after my marriage (S, Married without children, 25 years).

Discussion

The current research study is to assess the knowledge, risk perception, and reproductive decision-making factors among WwE from India. The quantitative results of this current study provided information of the participants' understanding related to knowledge, risk perception, and reproductive decision-making factors. In contrast, the qualitative content analysis provided valuable detailed information that augmented additional insight into the study's quantitative findings. The results have similarities in some of the components related to the knowledge and risk perception and reproductive decision-making factors among WwE. Four superordinate themes that came across through the accounts of these women were general misconceptions about the illness, marriage and sexuality-related concerns, epilepsy, taking AEDs and pregnancy-related concerns, and concerns about the outcomes of the pregnancy.

Many of the WwE ($n = 37$, 75.5%) are literates but still have limited knowledge about epilepsy, and have misconceptions about the illness and concerns with pregnancy-related outcomes. This could be due to the lack of awareness about epilepsy, religious practices, sociocultural barriers to treatment, and lack of health care resources. A recent study from India has explored the sociocultural barriers to epilepsy treatment and it says that the treatment strategies for epilepsy were adaptation of traditional healers instead of western model of medical management.[13] Another study from India has reported that cultural beliefs were one of the factors which led to increase in the treatment gap in epilepsy.[14] As per the recent data, there is one neurologist for one million people in India,[15] leading to treatment gap to primary health care centers. High treatment cost, lack of availability and accessibility of health care services, stigma, and lack of awareness about the management of epilepsy were some of the factors contributing to the treatment gap.

In the present finding, $n = 46$ (93.9%) of the subjects reported that they would disclose their illness to the spouse or partner, which is promising and shows subject's positive attitude and education levels. However, 16 subjects (both married and unmarried WwE) have expressed their concern related to revealing their illness. This could be because of dearth of an insight about epilepsy, and stigma in the community. Information, education, and communication materials can be effective interventions at individual and group levels, both for the WwE and their family members. In the current study, $n = 39$ (79.6%) subjects reported being afraid of carrying the illness to their children. A research study that collected data from 88 PwE have mentioned that participants said that the choice to have lesser children was connected with concerns like passing epilepsy onto a child,[16] which is similar to the current study's finding. The same study found a significance among choice to have lesser children and capability to care for a child ($p < 0.0001$).[16]

In the current study only one (25%) participant has reported concerns related to pressure from the family for planning a pregnancy. It could be due to the joint family system and Indian sociocultural background compared with the other countries, where having a child immediately after the marriage has been expected by the family members as a normal phenomenon. One participant (25%) has stated that she had perceived concern about the child rearing practices due to the fear that what if she gets seizure attacks during the

 © 2023. Indian Epilepsy Society. All rights reserved.

process of child rearing, which is at par with a previous Indian study.[17] Management of both sexual and reproductive health care is an essential factor among WwE. In the present study, a total of six (19.3%) participants have expressed not being able to discuss their sexual issues with a male neurologist. A recent qualitative study disseminated the barriers for the sexual and reproductive health care as patient or family members' discomfort, limited time, and lack of expertise.[18] Nearly one-fourth of the WwE ($n = 11$, 22.4%) have agreed that WwE cannot breastfeed the child and breastfeeding the child while on AEDs harms the development of the child.

A qualitative study from Iran have suggested that WwE were doubtful about breastfeeding the child after being educated and their concerns were exacerbated by the physician's inconsistent perspective about breastfeeding.[19] Nine participants (33.3%) have expressed concern about having AEDs and dose adjustments of AEDs (11.1%) during pregnancy. A qualitative study from Norway has revealed that dose adjustments of AEDs were a major concern for the pregnant WWE.[20] A recent content analysis qualitative study from Iran has advised that drug dose alteration was the anxiety-provoking factor among WwE during pregnancy.[19] A Korean study with the inclusion of 186 WwE has stated that regardless of medical suggestion 58% of WwE were in view of terminating AEDs during an imminent pregnancy, and 25% of WwE were chosen to have fewer children due to their epilepsy.[21,22] Low level pregnancy-related knowledge was connected with the choice to suspend the AEDs during a future pregnancy and an overstated insight of the children's risk for developing epilepsy was related to have fewer children. The findings throw light on the significance of edification on problems associated with the pregnancy and genetic risk counseling. Hence, it is therefore very important to educate and involve WwE in decision making about the choice of AEDs and offer preconception counseling.[23]

One possible social work intervention to address these exaggerated perceptions about risks related to the pregnancy, using AEDs medication and its outcomes should be conducting a peer support groups with the women who have experienced the pregnancy phase and giving a safe birth while on AEDs and those who have the positive outcomes and experiences will help the other women. The same has been suggested by a qualitative study from Norway saying that arranging support groups to the nulliparous women with the women who have experienced the pregnancy and giving birth while on AEDs can support them.[20] The majority of the participants (79.6%) in the present study have reported being afraid of their children developing epilepsy. The same abovementioned study has concluded that choice to have fewer children was associated with the magnified acuity of the risk for children to developing epilepsy.[21] A qualitative study from the United Kingdom also found that mothers of children with undiagnosed developmental delay have reported that perception of risk was one of the influencing reproductive decision-making factors.[24] Six participants (12.2%) have expressed that they have decided to not plan for a child due to the past undesired experiences during pregnancy. A research study from Australia in their content analysis research demonstrated that pregnant WwE perceptions of the risk were intensified by their previous experiences.[25]

A prospective study has stated that the toxic effects of the AEDs was one of the major concerns reported by WwE.[26] In our study, both unmarried and married with and without children have expressed concern about the potential side effects of the AEDs. Irrespective of married or not, having children or not is a common concern expressed by all. Some of the participants have given reasons for their concern related to the influence of spouse, family members, friend's choices to continue the medication, limited knowledge about AEDs, and myths about the AEDs. There is a need to develop interventions to reduce risk management and risk perception and increase treatment adherence and knowledge about this illness. Qualitative research from the United Kingdom has found that using the toolkit was helpful to increase the knowledge about epilepsy and risk management.[27] A study from India has stressed upon the importance of conducting sessions to enhance awareness about epilepsy, to understand the concerns among WwE. The same study has also advised that a well-planned education in this area to all health care professionals is essential to improve the understanding and care of WwE.[28] One participant (25%) has reported that safety of the AEDs was one among the reproductive decision-making factor. A retrospective study from Japan has mentioned that planning of pregnancy among WwE is associated with the safety of AEDs.[29]

Some of the participants have reported concerns about the outcomes of the pregnancy on child's development, intelligence, birth weight, and congenital disabilities. Various sociocultural factors will impact the outcomes of the pregnancy, a study from South India has cited the influence of pregnancy outcomes on multiple factors such as geographic and environmental factors, ethnic background, and socioeconomic status of the participants.[30] A review study from Norway has demonstrated that seizure attacks could also affect the cognition, size of the child, and also impact neurodevelopmental and malformation of the child.[31] A phenomenological study from Sweden has demonstrated that WwE were concerned about the usage of AEDs due to the teratogenic affects and other pregnancy risks associated.[32] Some of the WwE ($n = 4$, 8.16%) have concern about the health of the child, the findings are at par with the following study which showed that 46.0% of the WwE population did not believe that they will have healthy children.[33] All the above stated concerns by the WwE can be given importance to address the issues.

We recommended development of information, education, and communication materials on promoting awareness about epilepsy, its myths, and facts. Special attention should be given to the WwE during their reproductive age to discuss about their concerns by the family physicians. The family physicians should work with multidisciplinary team in the management of concerns with WwE in providing optimal care and quality of life for WwE. There should be female

 © 2023. Indian Epilepsy Society. All rights reserved.

counselors or clinical social workers to address the needs of WwE in tertiary care centers. Sensitizing health care workers about the significance of purposeful discussions in the field of epilepsy management is a must.

Limitation and Conclusion

The findings of the study cannot be generalized to the other cultural backgrounds. However, the current findings throw light on the significance of edification on problems associated with pregnancy and genetic risk counseling. This is the first study in India that explored culturally relevant misconceptions and knowledge gap among WwE in the clinical setting. Women require special care and attention compared to men, which minimizes the risk of perception related to reproductive health issues among WwE.

Funding
This study was funded by UGC, New Delhi, India.

Conflict of Interest
None declared.

Acknowledgments
The researchers thank all the WwE and their relatives for contributing their precious time to be a part of this study. This research would not have been possible without their generous support.

References

1 Amudhan S, Gururaj G, Satishchandra P. Epilepsy in India I: epidemiology and public health. Ann Indian Acad Neurol 2015; 18(03):263–277
2 Garg D. Specific considerations for epilepsy in India. Curr Med Issu 2020;18(02):105–110
3 Thomas SV. Managing epilepsy in pregnancy. Neurol India 2011; 59(01):59–65
4 Morrell MJ. Effects of epilepsy on women's reproductive health. Epilepsia 1998;39(Suppl 8):S32–S37
5 Santhosh NS, Sinha S, Satishchandra P. Epilepsy: Indian perspective. Ann Indian Acad Neurol 2014;17(Suppl 1):S3–S11
6 Sridharan R, Murthy BN. Prevalence and pattern of epilepsy in India. Epilepsia 1999;40(05):631–636
7 Sachin S, Padma MV, Bhatia R, Prasad K, Gureshkumar C, Tripathi M. Psychosocial impact of epilepsy in women of childbearing age in India. Epileptic Disord 2008;10(04):282–289
8 Radhakrishnan K, Pandian JD, Santhoshkumar T, et al. Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. Epilepsia 2000;41(08):1027–1035
9 Aydemir N, Kaya B, Yıldız G, Öztura I, Baklan B. Determinants of felt stigma in epilepsy. Epilepsy Behav 2016;58:76–80
10 Thomas SV, Bindu VB. Psychosocial and economic problems of parents of children with epilepsy. Seizure 1999;8(01):66–69
11 Fisher RS, Cross JH, French JA, et al. Operational classification of seizure types by the International League Against Epilepsy: position paper of the ILAE Commission for Classification and Terminology. Epilepsia 2017;58(04):522–530
12 Srikanth P, Vranda MN, Thomas PT, Raghvendra K. Quality of life and stigma among women with epilepsy during their reproductive years. J Epilepsy Res 2021;11(01):63–71
13 Rani A, Thomas PT. Parental knoweldge, attitude, and perception about epilepsy and sociocultural barriers to treatment. J Epilepsy Res 2019;9(01):65–75
14 Santosh D, Kumar TS, Sarma PS, Radhakrishnan K. Women with onset of epilepsy prior to marriage: disclose or conceal? Epilepsia 2007;48(05):1007–1010
15 The future of neurology in India [Internet]. Worldneurologyonline.com. Accessed May 6, 2022 at: https://worldneurologyonline.com/article/the-future-of-neurology-in-india/
16 Helbig KL, Bernhardt BA, Conway LJ, Valverde KD, Helbig I, Sperling MR. Genetic risk perception and reproductive decision making among people with epilepsy. Epilepsia 2010;51(09):1874–1877
17 Saramma PP, Sarma PS, Thomas SV. Women with epilepsy have poorer knowledge and skills in child rearing than women without epilepsy. Seizure 2011;20(07):575–579
18 Kirkpatrick L, Collins A, Sogawa Y, Birru Talabi M, Harrison E, Kazmerski TM. Sexual and reproductive healthcare for adolescent and young adult women with epilepsy: a qualitative study of pediatric neurologists and epileptologists. Epilepsy Behav 2020; 104(Pt A):106911
19 Atarodi-Kashani Z, Kariman N, Ebadi A, Majd HA, Beladi-Moghadam N, Hesami O. Exploring the perception of women with epilepsy about pregnancy concerns: a qualitative study. Electron Physician 2018;10(05):6843–6852
20 Widnes SF, Schjøtt J, Granas AG. Risk perception and medicines information needs in pregnant women with epilepsy–a qualitative study. Seizure 2012;21(08):597–602
21 Lee SM, Nam HW, Kim EN, et al. Pregnancy-related knowledge, risk perception, and reproductive decision making of women with epilepsy in Korea. Seizure 2013;22(10):834–839
22 Weckesser A, Denny E. Women living with epilepsy, experiences of pregnancy and reproductive health: a review of the literature. Seizure 2013;22(02):91–98
23 Bangar S, Shastri A, El-Sayeh H, Cavanna AE. Women with epilepsy: clinically relevant issues. Funct Neurol 2016;31(03):127–134
24 Pond E, Dimond R. Reproductive decision making: interviews with mothers of children with undiagnosed developmental delay. J Community Genet 2018;9(03):315–325
25 Carolan MC. Towards understanding the concept of risk for pregnant women: some nursing and midwifery implications. J Clin Nurs 2009;18(05):652–658
26 Kochen S, Salera C, Seni J. Pregnant women with epilepsy in a developing country. Open Neurol J 2011;5(01):63–67
27 Morley K. Reducing risks for pregnant women with epilepsy: a qualitative study exploring experiences of using a toolkit at the antenatal booking appointment. Epilepsy Behav 2020;103(Pt B):106418
28 Bhat M, Ramesha KN, Nirmala C, Sarma PS, Thomas SV. Knowledge and practice profile of obstetricians regarding epilepsy in women in Kerala state, India. Ann Indian Acad Neurol 2011;14(03):169–171
29 Abe K, Hamada H, Yamada T, Obata-Yasuoka M, Minakami H, Yoshikawa H. Impact of planning of pregnancy in women with epilepsy on seizure control during pregnancy and on maternal and neonatal outcomes. Seizure 2014;23(02):112–116
30 Thomas SV, Jose M, Divakaran S, Sankara Sarma P. Malformation risk of antiepileptic drug exposure during pregnancy in women with epilepsy: results from a pregnancy registry in South India. Epilepsia 2017;58(02):274–281
31 Sveberg L, Svalheim S, Taubøll E. The impact of seizures on pregnancy and delivery. Seizure 2015;28:35–38
32 Räty LK, Wilde-Larsson BM. Patients' perceptions of living with epilepsy: a phenomenographic study. J Clin Nurs 2011;20(13-14):1993–2002
33 Dierking C, Porschen T, Walter U, Rösche J. Pregnancy-related knowledge of women with epilepsy - an internet-based survey in German-speaking countries. Epilepsy Behav 2018;79:17–22

 © 2023. Indian Epilepsy Society. All rights reserved.