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# Impact of neurological diseases on family planning

### A single-center experience

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#### Abstract

This cross-sectional study aimed to assess the impact of epilepsy, myasthenia gravis (MG), and multiple sclerosis (MS) on pregnancy and family planning decision-making in a cohort of Saudi women. Women with epilepsy, MG, and MS were recruited consecutively at the time of their follow-up visits at a neurology clinic. Data were collected using 3 standardized questionnaires, and presented using descriptive statistics. A logistic regression was performed to determine variables associated with decisions regarding abstaining from pregnancy and encouraging other women to conceive. A total of 272 (83 epilepsy, 69 MG, and 120 MS) women with a mean age of 29.9±8.0 years participated. The proportion of women who abstained from or postponed pregnancy was 41.2% and 31.4%, respectively. The concerns mentioned most often were disease worsening during pregnancy, peripartum and postpartum, side effects of medications on the unbom child, and inability to care for the child. Older age was independently associated with the decision to abstain from pregnancy (odds ratio [OR] 1.14, 95% confidence interval [CI] 1.04 - 1.25). Higher knowledge levels were independently associated with encouraging other women to have children (OR 1.3, 95% CI 1.11–1.53). Over 50% of women reported that they were not counseled on issues related to pregnancy and childbirth. In conclusion, we identified a major influence of epilepsy, MG, and MS on pregnancy and family planning. Comprehensive counseling programs are needed to help women with these neurological diseases make informed family-planning decisions.

**Abbreviations:** AED = anti-epileptic drugs, CI = confidence interval, CNS = central nervous system, ICU = intensive care unit, IQR = interquartile range, MG = myasthenia gravis, MS = multiple sclerosis, OR = odds ratio, RRMS = relapsing-remitting variant, SD = standard deviation, WWE = women with epilepsy.

Keywords: epilepsy, family planning, multiple sclerosis, myasthenia gravis, pregnancy, Saudi Arabia

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The datasets generated during and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

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#### 1. Introduction

Women of childbearing age are often afraid of the effects of the disease or adverse effects of disease-specific medications on the development of the fetus and health of their child following birth. Myasthenia gravis (MG), multiple sclerosis (MS), and epilepsy are some of the more common neurological diseases that women may have at childbearing age. MG is an autoimmune disease that affects the neuromuscular junction and manifests with fatigable ptosis and diplopia, and weakness of bulbar, facial, and limb muscles. Patients with MG usually require treatment with immunosuppressive therapy including steroids and steroidsparing immunosuppressant. MS is an autoimmune, predominantly demyelinating, disease of the central nervous system (CNS) and generally presents as a relapsing-remitting variant (RRMS). MS has a plethora of clinical manifestations reflecting the different localizations of CNS pathology. These include optic neuritis, sensory symptoms, ataxia, and weakness. Patients with RRMS require disease-modifying therapy. Contrasting MG and MS, epilepsy is not an autoimmune disease, but rather involves recurrent attacks of seizures and is treated with one or more antiepileptic drugs (AED). Treatment periods with AED generally extend from a few years to lifetime use.

The impact of these neurological diseases on family planning has not been studied in Saudi Arabia. Ohlraun et al<sup>[1]</sup> reported that 71.7% of women with MG who had not completed their family planning before onset of MG, reported that they abstained from or delayed pregnancy. The most frequent concern reported was regarding the possible influence of MG medication on the unborn child (87.1%).<sup>[1]</sup> With regards to MS, 29.8% of women with MS chose not to reproduce, and "symptoms interfering with parenting" was the most common (75%) MS-related reason for their decision.<sup>[2]</sup> Regarding women with epilepsy (WWE), a major reason for abstinence from pregnancy was a concern about the risk of teratogenicity from AEDs.<sup>[3]</sup> In general, the risk of teratogenicity ranges from 2% to 8%, depending on the AED used, with the highest risk associated with valproate.<sup>[4]</sup> Seizure freedom for a minimum of 9 months before pregnancy increases the chance (84%–92%) of remaining seizure-free during pregnancy.<sup>[5]</sup>

Although these studies point to the importance of neurological disease consideration during family planning in the western world, the results may not translate to Middle Eastern/Arabic women due to differences in culture, values, beliefs and religion. Therefore, this study was conducted to assess the impact of epilepsy, MG, and MS on pregnancy and family planning decision-making in a cohort of Saudi women with these neurological conditions. We also explored factors that may influence these decisions and patients' perception of the role of neurologists in counseling.

#### 2. Methods

#### 2.1. Participants and data collection

This was a cross-sectional questionnaire-based study. All female patients who were diagnosed with epilepsy, MG, or MS and registered with adult neurology subspecialty clinics (epilepsy, neuromuscular, and MS clinics) at King Saud University Medical City (KSUMC) were recruited consecutively at the time of their follow-up visits. Patients with intellectual disability were excluded. The study commenced on December 5, 2018, and ended on March 31, 2019. Patients were asked to complete questionnaires in the waiting area before, or immediately after, their clinic visit. The questionnaires were made available online for those who preferred to have a link to complete them at home. The questionnaires were completely anonymous. All patients who completed a hard copy at the time of their appointments signed an informed consent and parents' permission was obtained for those <18 years of age. Patients who opted to use the online survey had to click an icon "agree to participate" before proceeding with the survey. The study was approved by the institutional review board at King Saud University (E-15-1661).

#### 2.2. Questionnaires

A committee of all authors developed 3 standardized questionnaires. Most of the items were generic for the 3 questionnaires. Initially, we reviewed a validated questionnaire developed by Ohlraun et al for patients with MG.<sup>[1]</sup> Permission from the corresponding author was granted. The committee maintained the themes of the items that were not influenced by the local culture or religion and added a few items concerning counseling and patients' levels of knowledge. All items of the provisional questionnaire were written in Arabic. The provisional version was divided into the following sections: general information, information about the disease, which included mostly generic items except questions on subtypes of the disease, knowledge about pregnancy-related issues, which included 12 questions specific for each disease group rated as true, false, or I do not know, information about pregnancy, information about family planning, and information about counseling. To ensure anonymity of the survey, no identifying data were requested. Subsequently, the questionnaires were reviewed by 15 patients (5 from each disease group) for readability, comprehension and relevance. In total, 3 revisions of the questionnaires were tested before the final version was produced.

The questionnaires are available as an online supplementary material, http://links.lww.com/MD/F113. For patients who were single or unemployed, the questionnaires asked whether their status was due to the disease (hereafter referring to epilepsy, MG, or MS according to the respective disease group) or other reasons. For married women, the items queried about the following: conception after the diagnosis had been made; disease status during pregnancy and postpartum (improved or worsened); previous miscarriages and their cause; number of children; disease influence on family planning (partial influence, major influence, no influence) and to what extent (postponing or abstaining pregnancy, moving forward with having more children, or undecided), and reasons for postponing pregnancy. For all patients, additional queried items were: age at symptom onset and at diagnosis; disease control status at present time; patient's perception of impairment caused by the disease; previous intensive care unit (ICU) admission due to a relapse or attack of the disease; time of the last disease relapse/attack; patients' perception of neurologist's role in counseling; patient's advice to other women with the same disease who consider pregnancy, and whether their neurologists counseled them on pregnancy- and childbirth-related issues.

#### 2.3. Analysis

Descriptive statistics were reported as mean and standard deviation  $(M \pm SD)$  for continuous variables, and as median, interquartile range (IQR), and percentages for categorical variables. A 1-way analysis of variance with post-hoc Tukey test, and a Kruskal-Wallis test followed by Mann-Whitney U tests were employed, when appropriate, to compare continuous and categorical variables between the 3 disease groups, respectively. The sum of correct answers of the 12 knowledge questions was calculated for every patient. Univariate logistic regression was employed to test variables that had significant association with the decision to abstain from pregnancy, and to test variables that had significant association with encouraging other women to conceive. Variables with a significant association during univariate analysis were entered in a multivariate logistic regression model, adjusted for age and disease group. Independent variables were age, education, total knowledge score, previous ICU admission, time of the most recent disease relapse/ attack, previous experience of pregnancy, previous experience of miscarriage, patients' perception of disease control, and patients' perception of the impairment caused by their disease.

A 2-tailed *P* value <.05 was considered significant. For multiple paired comparisons we used a Bonferroni-corrected *P* value <.017 to indicate significance. The statistical software SPSS (version 22; SPSS Inc, Chicago, IL) was used for data analysis.

#### 3. Results

A total of 272 (83 epilepsy, 69 MG, and 120 MS) women participated in the study. Demographic data are presented in Table 1. Due to missing data, response rates were reported for each item. The mean age for all participants was  $29.9 \pm 8.0$  years. Age at symptom onset and at diagnosis is shown in Table 2. There was no significant difference in the average time between symptom onset and diagnosis among the 3 disease groups (P=.23). Table 1

Demograp	hics and ch	aracteristics	of the stu	dy population.

Variable	Value	
Age, $(M \pm SD)$ , y	29.9±8.0	
Education (highest degree)		
≤Grade 12	99/245 (40.4%)	
>Grade 12	146/245 (59.6%)	
Marital status		
Single	115/246 (46.7%)	
Married	111/246 (45.1%)	
Divorced or widowed	20/246 (8.1%)	
Employment status		
Employed	61/233 (26.2%)	
Not employed because of the disease	31/233 (13.3%)	
Not employed for other reasons	141/233 (60.5%)	
Disease		
Epilepsy	83/272 (30.5%)	
MG	69/272 (25.4%)	
MS	120/272 (44.1%)	
MG type		
Ocular	6/69 (8.7)	
Generalized	42/69 (60.9)	
I do not know	21/69 (30.4)	
MS type		
RRMS	53/120 (44.2)	
PPMS	5/120 (4.2)	
SPMS	11/120 (9.2)	
PRMS	1/120 (0.8)	
I do not know	50/120 (41.7)	

$$\label{eq:memory} \begin{split} M = mean, \ MG = myasthenia \ gravis, \ MS = multiple \ sclerosis, \ PPMS = primary \ progressive \ MS, \\ PRMS = progressive \ relapsing \ MS, \ RRMS = relapsing-remitting \ MS, \ SD = standard \ deviation, \\ SPMS = secondary \ progressive \ MS. \end{split}$$

#### 3.1. Education

Education level above grade 12 was reported by 37 of 82 (45.1%), 36 of 57 (63.2%), and 73 of 106 (68.9%) epilepsy, MG, and MS patients, respectively (Table 1). A significantly higher proportion of MS patients had an education level above grade 12 than that of epilepsy patients (P < .01). No significant difference was found in the paired comparison of MG and epilepsy (P=.037) or MG and MS (P=.46).

#### 3.2. Social status and employment

The number of married and single women was approximately equal in our cohort (Table 1). Of the single women, 22 of 101 (21.8%) reported that they refused marriage because of their illness, 2 of 101 (2.0%) reported that their family did not encourage them to get married because of their illness, and 8 of 101 (7.9%) reported a breakdown from the fiancé's side after knowing about their illness. Two women with epilepsy reported the termination of marriage after the diagnosis was confirmed. Only 61 of 233 (26.2%) women were employed. There was no significant difference in social status (P=.8) or employment status (P=.06) between the 3 disease groups.

#### 3.3. Participants' Knowledge About the Influence of Epilepsy, MG and MS on Pregnancy and Vice Versa Was Overall Low

The total knowledge score for all participants ranged from 0 to 11 out of 12, with a median score of 6 and IQR of 2 to 8 (Table 2).

#### Table 2

Disease-related information for the study population.

Variable	Value
Age at symptoms onset, (M $\pm$ SD) y	20.5±8.5
Age at diagnosis, $(M \pm SD)$ , y	$22.4 \pm 8.3$
ime between diagnosis and participation,	7.3±6.8
$(M \pm SD), y$	
eriod between symptom onset and diagnosis,	
Epilepsy	$2.2 \pm 5.2$
MG	$1.7 \pm 3.6$
MS	1.0±2.2
Previous ICU admission due to a relapse/	49/222 (22.1)
attack, N (%)	9/76 (10 5)
Epilepsy MG	8/76 (10.5) 25/52 (48.1)*
MS	16/94 (17.0)
Age at the ICU admission, $(M \pm SD)$ , y	$23.6 \pm 8.6$
Viscarriages/total pregnancies, N (%)	20/166 (12.0)
Epilepsy	4/63 (6.3)
MG	9/40 (22.5)*
MS	7/63 (13.0)
A partial or major disease impact on family pla	anning, N (%)
Epilepsy	9/32 (28.1)
MG	18/34 (52.9)*
MS	22/44 (50.9)
Patients' perception of current impairment by t	
Not impaired	111/226 (49.1)
Mild impairment	52/226 (23.0)
Moderate impairment	48/226 (21.2)
Severe impairment Patients' report of current disease status, N (%	15/226 (6.6%)
Controlled with or without medications	°) 79/223 (35.4)
Relatively controlled	86/223 (38.6)
uncontrolled	34/223 (15.2)
l do not know	24/223 (10.8)
A controlled or relatively controlled disease, N	
Epilepsy	60/70 (85.7)
MG	35/51 (68.6) <sup>  </sup>
MS	70/78 (89.7)
The most frequent medication used in women	with epilepsy
Levetiracetam	49/83 (59.0)
Depakote	16/(19.3)
Lamotrigine	13/(15.7)
he most frequent medication used in women	
Pyridostigmine	34 (49.3)
Prednisolone	30 (43.5)
Thymectomy The most frequent medication used in women	25 (36.2) with MS
Interferons	25 (20.8)
Fingolimod	22 (18.3)
Natalizumab	18 (15.0)
Patients' report of change in disease status du	
Epilepsy (total $N = 20$ ), improved/	2 (10)/1 (5)
worsened	. / . /
MG (total N=10), improved/worsened	5 (50)/2 (20)
MS (total N=23), improved/worsened	10 (43.5)/2 (8.7)
Patients' report of change in disease status po	
Epilepsy (total N=20), improved/	3 (15)/1 (5)
worsened	0/4 / 20
MG (total N = 10), improved/worsened	0/4 (40)
MS (total N = 23), improved/worsened	1 (4.3)/8 (34.8)
Knowledge score out of 12, N (%)	C 1 /1 00 /00 0
0–3 4–6	64/192 (33.3)
4–6 7–9	48/192 (25.0)
7–9 10–12	64/119 (33.3) 16/192 (8.3)
	10/132 (0.3)

 $\label{eq:ICU} ICU = \text{intensive care unit, M} = \text{mean, MG} = \text{myasthenia gravis, MS} = \text{multiple sclerosis, SD} = \text{standard deviation.}$ 

\*P < .001 for MG vs epilepsy, and for MG vs MS.

<sup>†</sup> P=.017 for MG vs epilepsy.

 $^{\ddagger}P < .015$  for MG vs epilepsy.

 ${}^{\$}P$  < .01 for MG vs epilepsy, and P=.017 for MG vs MS.

|| P < .01 for MS vs MG.

Twenty-nine (10.7%) patients answered all questions incorrectly. The median knowledge scores for epilepsy, MG, and MS patients were 5 of 12 (IQR 2–7), 6 of 12 (IQR 3–8), and 5 of 12 (IQR 2–8), respectively. The Kruskal-Wallis test showed no significant differences in the total knowledge score between the three disease groups (P=.22).

#### 3.4. MG Causes Higher Perception of Impairment and Less Disease Control Than MS and Epilepsy

Perception of any degree of impairment due to the disease was reported by 34 of 81 (42.0%) epilepsy patients, 36 of 51 (70.5%) MG patients, and 45 of 94 (47.9%) MS patients (Table 2). Perception of any degree of impairment was reported by a higher proportion of patients with MG than epilepsy (P < .01), and MS (P=.017). There was no difference in the perception of impairment between MS and epilepsy patients, P=.25. A disease status of controlled or relatively controlled was reported by 60 of 70 (85.7%) epilepsy patients. A significantly less proportion of MG patients reported a controlled or relatively controlled disease status than MS patients (P < .01), and no significant difference in the paired comparison of MG and epilepsy (P=.024), or MS and epilepsy (P=.46).

#### 3.5. ICU admission

Previous critical care unit admission due to a disease attack/ relapse was reported by 49 of 222 (22.1%) women, with a mean age at admission of  $23.6 \pm 8.6$  years (Table 2). The number of patients with previous ICU admissions were significantly higher in MG than MS and epilepsy (P < .001). The difference between MS and epilepsy in the number of ICU admissions was not statistically significant.

#### 3.6. Disease Impact on Family Planning

With respect to family planning, 36 of 110 (32.7%) women reported no influence from their disease on family planning, 35 of 110(31.8%) reported a partial influence, and 14 of 110(12.7%)reported a major influence (Table 2). The remainder reported a completion of family planning before the diagnosis was made. A significantly higher number of MG patients reported a partial or major influence of their disease on family planning than that of epilepsy patients (P = .015); no other differences through paired comparisons were found. The influence of disease on family planning was in the form of abstaining from pregnancy in 21/51 (41.2%), postponing pregnancy in 16 of 51 (31.4%), and having more children before the disease worsened in 6 of 51 (11.8%), and the remainder were undecided. Reasons cited for abstaining or postponing pregnancy are shown in Table 3. In univariate logistic regression analyses, only older age (odds ratio [OR] 1.14, 95% confidence interval [CI] 1.04-1.25) was significantly associated with abstinence from pregnancy (N=49).

#### 3.7. Disease impact on pregnancy

Approximately half (60/111, 54.1%) of women conceived after disease diagnosis (Table 2). In total, there were 20 miscarriages of 166 pregnancies (12.0%). Miscarriages occurred in 15 women (1 woman had 3 miscarriages, 3 had 2 miscarriages, and 11 had 1 miscarriage). The Kruskal–Wallis test showed a significant

#### Table 3

Reasons cited by female patients for their decision to postpone or abstain from pregnancy (total responses 37).

Reason	No. (%)
Worried about the effect of the disease on my health	23 (62.2%)
Concern that the disease might get worse during pregnancy	26 (70.3%)
Worried about not having enough strength for delivery	22 (59.5%)
Worried about disease relapse during delivery	26 (70.3%)
Worried about disease worsening after delivery	21 (56.8%)
Worried about effect of medications on the unborn child	25 (67.6%)
Worried about not having enough strength to take care of the baby	24 (64.9%)
Concern that the child might get the same disease	18 (48.6%)
Because of my previous experience with miscarriage	5 (13.5%)
Because of my previous experience of having a child with congenital malformation	1 (2.7%)

difference in the number of miscarriages between the three disease groups (P=.048), and MG was the highest. Worsening in disease status during pregnancy was reported by 5 of 53 (9.4%) women, whereas improvement was reported by 17 of 53 (32.1%) women. Disease status postpartum improved in 4 of 53 (7.5%) and worsened in 13 of 53 (24.5%). The remainder reported either no or variable changes in disease status during pregnancy and in the postpartum period. There was no significant difference in disease status during pregnancy (P=.06) or postpartum (P=.64) between the 3 disease groups.

#### 3.8. Participants' Advice to other Women Regarding Family Planning Issues

Overall, 132 of 190 (69.4%) participants would encourage women with the same disease to have children, whereas 20 of 190 (10.5%) discouraged them. The latter group had concerns about mothers' health and care/fairness for the baby. Regarding participants' advice to other women with the same disease who are considering pregnancy, 142 of 184 (77.2%) agreed that the disease should not be an obstacle from having children if the neurologist has no concerns, and 122 of 182 (67.0%) agreed that pregnancy should be considered only in the setting of a stable and supportive environment. In univariate logistic regression analyses, higher levels of knowledge (P < .001), absence of previous ICU admission (P=0.049), and experience of pregnancy after diagnosis (P=.02) were associated with encouraging other women to have children. In a multivariate logistic regression analysis, only higher level of knowledge (OR 1.3, 95% CI 1.11-1.53) was associated significantly with encouraging other women to have children (N=97).

## 3.9. Participants' Perception of the Neurologist's Role in Counseling

This section included all participants irrespective of their social status, 142 of 179 (79.3%) of them thought that the neurologist should ask all women of childbearing age who have the same disease if they want to have children. In addition, 104 of 176 (59.1%) thought the neurologist should raise this issue only when discussing medication side effects, 148 of 178 (83.1%) thought the neurologist should give pregnant patients close follow-up appointments, and only 18 of 177 (10.2%) thought the neurologist should not interfere as it is a task of the obstetrician.

Table 4

Counseling items	Yes, no. (%)
Did the doctor ask you if you desire or planning to have children?	67/181 (37.0
Did the doctor answer your questions satisfactorily?	124/177 (70.1)
Did the doctor explain the potential effect of the pregnancy on the disease?	74/175 (42.3)
Did the doctor explain the potential effect of the disease on pregnancy/baby?	68/174 (39.1
Did the doctor explain the potential side effects of the medications on pregnancy/unborn baby?	72/174 (41.4)
Did the doctor explain the need to plan pregnancy early in order to control the disease and make any necessary changes in medications before conception?	80/177 (45.2

Of all married women, 59 of 111 (53.2%) reported that they had sought their doctor's opinion at the time of pregnancy planning. Table 4 shows patients' reports of the counseling items that had been discussed with them by their neurologists.

Of the total, only a small number of patients had comorbidities as following: diabetes (8), hypertension (5), dyslipidemia (1), hypothyroidism (9), depression (19), anxiety (1), bronchial asthma (15), systemic lupus erythematosus (4), rheumatoid arthritis (1), breast cancer (2), colon cancer (1), coronary artery disease (1), ulcerative colitis (1), anemia (2), vitiligo (1), obsessive compulsive disorder (1), pityriasis rosea (1), and insomnia (1).

#### 4. Discussion

This study revealed a major influence of epilepsy, MG, and MS on the decision to conceive in a group of women from Saudi Arabia. Abstaining from and postponing pregnancy was reported by 41.2% and 31.4%, respectively. The corresponding numbers reported by women with MG in a similar study were 50.4% and 21.3%, respectively.<sup>[1]</sup> Regarding women with MS, a previous study showed that only 21.8% chose to conceive after diagnosis was made, and among those who abstained, 29.8% attributed it to "MS-related reasons."<sup>[2]</sup> These concerns were about the mother's and child well-being and coping with parenting.<sup>[2,6]</sup> Approximately, 40% of WWE who abstained from having children reported concerns about teratogenicity of AED among their reasons.<sup>[3]</sup> The most common reasons raised by women in our study were similar to those reported by Ohlraun et al and were mainly related to concerns regarding disease worsening during pregnancy, peripartum and postpartum, side effects of disease-specific medications on the fetus, and the inability to take care of the child.<sup>[1]</sup> Despite these concerns, a large proportion of the participants in this study would still encourage other women with the same disease to have children.

In this study, older age was the only variable that showed an association with abstinence from pregnancy. A possible reason for this finding may be that older women already had children by the time they were diagnosed, which may have influenced their decision toward not conceiving.

Approximately half of women became pregnant with a proportion of miscarriages of 12%. Collectively, this proportion of miscarriages is slightly more than that estimated for the general population in Saudi Arabia. In 2016, there were 266,184 total births and 24,927 spontaneous abortions in Ministry of Health Hospitals,<sup>[7]</sup> with an estimated proportion of miscarriages of 8.6%. Disease course during pregnancy was variable, whereby approximately one-third of participants reported improvement, one tenth reported worsening, and the remainder reported either no change or variable changes. The course of MG during pregnancy has been reported to be

variable; 30% to 50% of patients experience worsening of symptoms, mostly during the first or second trimesters, and some patients experience improvement in the third trimester.<sup>[8]</sup> In our study, both MG and MS showed a trend towards improvement during pregnancy and worsening in the postpartum period, which is consistent with the literature.<sup>[8,9]</sup> With regards to WWE, only 1 patient (5%) reported worsening of seizure control during pregnancy and postpartum, suggesting that most WWE in our cohort may have had good seizure control in the year before conception.<sup>[5]</sup>

It is crucial for women with epilepsy, MG and MS to be educated about the risks associated with these diseases and pregnancy to aid them when making informed decisions about family planning. In this study, patients' level of knowledge regarding pregnancy and childbirth was collectively low, with no significant difference between the three diseases. This was also supported by the relative lack of knowledge of their respective disease subtype and may be partially explained by their report of infrequent counseling conducted by neurologists. Low levels of patient knowledge in the context of epilepsy, MG, and MS has been observed in previous studies.<sup>[1,3,10]</sup> Overall, >50% of women reported not receiving information from their neurologists regarding issues related to pregnancy and childbirth with respect to their disease, which is in agreement with a previous report in WWE.<sup>[3]</sup>

The role of neurologists in counseling, was well accepted by our cohort as has been reported in other studies.<sup>[1,3]</sup> This study did not explore physicians' perspectives on the barriers that may limit patients counseling; however, one possible reason may be related to the short time assigned for each visit due to clinic overload with patients. Another possible reason is recall bias; for example, review of physicians' notes have revealed that 25% of patients who denied having received counseling by their physicians were actually counseled.<sup>[11]</sup> This emphasizes the importance of using other sources of information, such as written materials, to educate patients and consolidate the knowledge delivered verbally by their physicians.<sup>[3]</sup>

Our data suggest that the perception of impairment in patients with MG is more than that in patients with MS and epilepsy. This is also supported by the higher number of patients who reported ICU admissions due to an MG relapse than those who reported ICU admissions with an MS or epilepsy relapse. In general, adverse effects of disease-specific therapy may contribute to the perception of impairment reported by our patients. In addition, fatigue, a subjective feeling of physical and mental exhaustion, likely contributed to the patients' reports of impairment in this study. The prevalence of fatigue in MG has been reported to be  $56.1\%^{[12]}$  and  $70\%^{[13]}$  in 2 different studies. In MG, patients' levels of fatigue have been shown to correlate with disease severity and to be worse in women<sup>[13,14]</sup>; however, fatigue was also reported by a third of patients in pharmacological remission.<sup>[12]</sup> In MS, besides functional limitations caused by the accumulated deficits, excessive fatigue remains one of the most disabling symptoms.<sup>[15]</sup> Patients with epilepsy were the least to report disease-related impairment. This is possibly explained by the nature of the disease whereby patients return to normal state between seizures. Additionally, this may also indicate an overall good seizure control in our cohort.

The reported unemployment rate among Saudi women in the first quarter of 2019 was 31.7%.<sup>[16]</sup> However, this estimate used some preliminary data and included only individuals who were registered in the government sectors or the General Organization for Social Insurance.<sup>[16]</sup> In this study, approximately three-fourths of women with neurological diseases were unemployed, but only a minority (13.3%) attributed that to their illness. This low rate is reassuring; however, the impact of neurological diseases on employment merit further studies.

This study has several limitations. In addition to the inherent limitations of cross-sectional questionnaire-based studies including missing data, the findings were based on patients' report, in which we cannot exclude subjectivity and bias, especially in items related to "impairment" and "counseling." Due to the study design, information regarding the Expanded Disability Status Scale for patients with MS, and MG Foundation of America classification for patients with MG were not obtained. There is also potential for recall bias in the responses to questions relying on memory. Furthermore, these results represent a single-center experience, which limit their generalizability.

In conclusion, we have reported a major influence of epilepsy, MG, and MS on pregnancy and family planning, which has resulted in abstaining from or postponing pregnancy in a large proportion of women. Low levels of knowledge regarding pregnancy- and childbirth-related issues, and patients' perception of inadequate counseling by neurologists were observed in the present study. We emphasize the need for comprehensive counseling programs supplemented by other methods of education such as written material to help women with neurological diseases make informed family-planning decisions. Future studies are needed to develop a family planning counseling program and evaluate its effect on the disease and pregnancy outcome.

#### **Author contributions**

MHA, AA, MFE, and ARA: Study concept and design, acquisition, analysis, and interpretation of data, and drafting of manuscript.

MHA and ARA: Statistical analysis, important intellectual content, and study supervision.

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