



# Theory of Planned Behavior including self-stigma and perceived barriers explain help-seeking behavior for sexual problems in Iranian women suffering from epilepsy



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## ABSTRACT

**Purpose:** To apply the Theory of Planned Behavior (TPB) and the two additional concepts self-stigma and perceived barriers to the help-seeking behavior for sexual problems in women with epilepsy.

**Methods:** In this 18-month follow-up study, TPB elements, including attitude, subjective norm, perceived behavioral control, and behavioral intention along with self-stigma and perceived barriers in seeking help for sexual problems were assessed in  $n = 818$  women with epilepsy (94.0% aged  $\leq 40$  years). The basic TPB model (model 1) and the TPB model additionally including self-stigma and perceived barriers (Model 2) were analyzed using structural equation modeling (SEM).

**Results:** Both SEM models showed satisfactory model fits. According to model, attitude, subjective norms, perceived behavioral control, and intention explained 63.1% of the variance in help-seeking behavior. Variance was slightly higher (64.5%) when including self-stigma and perceived barriers (model 2). In addition, the fit indices of the models were better highlighting the importance of self-stigma and perceived barriers in help-seeking behavior for sexual problems.

**Conclusion:** Theory of Planned Behavior is useful in explaining help-seeking behavior for sexual problems in women with epilepsy. Self-stigma and perceived barriers are additional factors that should be considered in future interventions aiming to adopt TPB to improve help-seeking behavior for sexual problems.

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## 1. Introduction

Sexual problems have detrimental effects on an individual's quality of life and overall well-being and not only impact on mental health and self-esteem, but may further lead to emotional distress, dyadic friction, and in some extreme cases even divorce [1–5]. According to a recent British study, nearly one-third of men and two-thirds of women avoid sex because of their sexual problems; yet less than 25% of those who reported sexual problems actively seek help [6]. In other words, the negative influence of a sexual problem may continue because of non-help-seeking behavior and lead to termination of relationships and marriages.

**Abbreviations:** AEDs, antiepileptic drugs; TPB, Theory of Planned Behavior; FSFI, Female Sexual Function Index; SSOSH, Self-Stigma of Seeking Help Scale; SEM, structural equation modeling; DWLS, diagonally weighted least squares; CFI, comparative fit index; TLI, Tucker-Lewis index; RMSEA, root mean square of error approximation; WRMR, weighted root mean square residual.

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Research has recently started to focus on the problem of non-help seeking for sexual problems in the general population but also in a variety of clinical samples [4,7–9]. It is therefore important to address this issue also in women suffering from epilepsy. A number of epidemiologic studies have suggested that women with epilepsy have an elevated risk of sexual problems (>70%) [10]. According to one such study, women with epilepsy had a significantly higher prevalence (75.3%) of sexual problems compared with the general adult population (12.0%), [11]. The range of sexual complaints in women with epilepsy is broad, with problems pertaining to libido, arousal, and orgasm problem representing those most commonly observed [12,13]. Though impaired sexual functioning has long been known to have detrimental effects on the quality of life of the patients and on couple satisfaction, many clinicians – including neurologists – tend to ignore the importance of sexual health in patients with epilepsy and do not consider it to be a treatment priority [14].

Regarding the causes, possible risk factors for sexual problems in women with epilepsy include earlier onset of menopause, epileptic activity in cortex, certain antiepileptic drugs (AEDs), anxiety, and stigmatization [15–18]. Therefore, the etiology of sexual dysfunction for

women with epilepsy is most likely multifactorial, wherein neurological, iatrogenic, endocrine, psychiatric, and psychosocial factors all seem to play a role [11]. Still, the specific etiology often remains unclear and has to be evaluated individually for each case [11,19,20]. Given the high rates of sexual problems in women with epilepsy and the low numbers of individuals actively seeking help for their problems, expanding our knowledge on the factors influencing help-seeking behavior for sexual problems in this specific clinical sample may be of interest for clinicians and researchers and may provide them the necessary input to design more effective and holistic interventions and treatment plans.

Theory of Planned Behavior (TPB) as proposed by Ajzen [21] is a potential framework that can be used to better understand the mechanism of help-seeking behavior for sexual problems in women with epilepsy. Previous evidence has shown that TPB can be used to explain medication adherence across different populations [22], including people with epilepsy [23], and numerous recent studies have used TPB to explain help-seeking behaviors for a broad range of conditions [24–27], including sexual problems [28].

Theory of Planned Behavior suggests three main factors that influence an individual's behavioral intention which subsequently affects the expression of the final behavior. The three factors are *attitude* (a person evaluates the positive or negative outcomes of performing the behavior), *subjective norm* (a person perceives whether his or her significant others approve or disapprove of the behavior), and *perceived behavioral control* (a person judges his or her capability to perform the behavior). Attitude and subjective norm are associated with final behaviors via behavioral intention, while perceived behavioral control seems to be indirectly (also through behavioral intention) linked to the final behavior [21,29]. Moreover, meta-analyses which support the validity of TPB across different health behaviors demonstrate that TPB can explain 19–36% of the variance in the final behavior and 40–49% of the variance in behavioral intention [22,30–32].

In order to maximize the explanatory potential of TPB, several additional factors such as self-stigma and perceived barriers in help seeking behavior can be incorporated in TPB. Self-stigma describes a set of negative attitudes toward help seeking [33,34] and may restrict an individual's motivation to change the situation or work on a problem [35–37]. A study on 281 Iranian women with sexual dysfunction echoes the influence of self-stigma by showing that ~10% of the participants did not seek for help because of shame [9]. Another study by Vahdaninia et al. [9] reported that ~40% of the participants did not seek help because of time constraints. Therefore, perceived barriers (especially physical burdens) could be another reason preventing women from seeking help for sexual problems.

### 1.1. Aims

Because of the previously suggested potential of TPB in explaining help-seeking behavior and the recent evidence of the negative effects of self-stigma and perceived barriers on behavioral intention, we aimed to evaluate two different models that may explain help-seeking behavior for sexual problems in a sample of Iranian women suffering from epilepsy. The first model (Model 1) included elements of traditional TPB such as attitude, subjective norm, perceived behavioral control, and behavioral intention to explain variance in help-seeking behavior for sexual problems. In the second model (Model 2) the two additional factors of self-stigma and perceived barriers were incorporated.

## 2. Material and methods

### 2.1. Participants

This 18-month follow-up study targeted female patients with epilepsy who had been referred to three university neurology clinics in the cities of Tehran and Qazvin. Inclusion criteria were 1) being 18 years or older; 2) a confirmed diagnosis of epilepsy; 3) being married

or having a partner; and 4) any kind of sexual problem as assessed by the Female Sexual Function Index (FSFI) (according to the suggested cut-off score of  $\leq 26.55$ ) [38,39]. Patients were excluded from the study if they 1) showed cognitive impairment as evaluated by the Mini Mental State Examination (score  $\leq 23$ ), and 2) did not agree to participate in the study. Two trained physicians identified the eligible participants from the registry data and subsequently contacted the patients to invite them to the study. Of the 1303 approached patients, 1081 patients (83%) attended an initial screening session where they were informed about the study aims and screened for sexual problems using the FSFI. The 818 (75.7%) patients reporting a sexual problem according to the FSFI were then invited to complete a series of study questionnaires for the assessment of help-seeking behavior (for more detailed information see Section 2.2.6) at baseline. Eighteen months later, information on help-seeking behavior for sexual problems was again collected.

The protocol for the study was approved by the ethics committee of Qazvin University of Medical Sciences and all participants provided a written informed consent before study participation.

### 2.2. Main outcome measures

#### 2.2.1. TPB questionnaire development

The TPB items were developed according to the guidelines of Azjen et al. [40,41]. For this, a convenience sample of females with epilepsy ( $n = 11$ ) was interviewed using a semi-structured interview. In this interview, women were presented with a hypothetical situation that they had been experiencing persistent from sexual dysfunction (disturbances in sexual desire, sexual arousal, and sexual pain and difficulty or inability to achieve an orgasm).

#### 2.2.2. Attitude toward help-seeking

Attitude was assessed using seven items: "For me to seek sexual health service is (1) extremely bad to extremely fine, (2) extremely negative to extremely positive, (3) extremely undesirable to extremely desirable, (4) extremely unimportant to extremely important, (5) extremely useless to extremely useful, (6) extremely disagreeable to extremely agreeable, and (7) extremely embarrassing to extremely unshameful." All responses were rated on a 5-point scale. Cronbach's  $\alpha$  of the seven items was 0.89 in the present study.

#### 2.2.3. Subjective norms

Three items were used to measure subjective norms (e.g., *my husband/partner thinks that I should seek sexual health service*). Each item was rated on a 5-point scale that ranged from 1 (strongly disagree) to 5 (strongly agree). Cronbach's  $\alpha$  of the three items was 0.90 in the present study.

#### 2.2.4. Perceived behavioral control

Perceived behavioral control was measured using 3 items (e.g., *seeking sexual health service is dependent on my choice*). Each item was rated on a 5-point scale that ranged from 1 (strongly disagree) to 5 (strongly agree). Cronbach's  $\alpha$  of the three items was 0.86 in the present study.

#### 2.2.5. Help-seeking intention

Three items were used to measure help-seeking intention (e.g., *I intend to seek sexual health service*). Each item was rated on a 5-point scale that ranged from 1 (strongly disagree) to 5 (strongly agree). Cronbach's  $\alpha$  of the three items was 0.88 in the present study.

#### 2.2.6. Help-seeking behavior in sexual dysfunction

The target behavior was actual visits to clinical psychologists, psychiatrists, gynecologists, or general practitioners for the sexual problem. The behavior was defined in terms of several elements including target (sexual health specialists: clinical psychologist, psychiatrist, gynecologist, and general practitioner), action (visiting sexual health specialists),

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