



Which information on women's issues in epilepsy does a community pharmacist need to know? A Delphi consensus study



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ABSTRACT

Objective: The aim of this study was to develop and achieve consensus on a core list of important knowledge items that community pharmacists should know on women's issues in epilepsy.

Methods: This was a consensual study using a modified Delphi technique. Knowledge items were collected from the literature and from nine key contacts who were interviewed on their views on what information community pharmacists should have on women's issues in epilepsy. More knowledge items were suggested by five researchers with interest in women's issues who were contacted to rate and comment on the knowledge items collected. Two iterative Delphi rounds were conducted among a panel of pharmacists ($n = 30$) to achieve consensus on the knowledge items to be included in the core list. Ten panelists ranked the knowledge items by their importance using the Analytical Hierarchy Process (AHP).

Results: Consensus was achieved to include 68 knowledge under 13 categories in the final core list. Items ranked by their importance were related to the following: teratogenicity (10.3%), effect of pregnancy on epilepsy (7.4%), preconception counseling (10.3%), bone health (5.9%), catamenial epilepsy (7.4%), menopause and hormonal replacement therapy (2.9%), contraception (14.7%), menstrual disorders and infertility (8.8%), eclampsia (2.9%), breastfeeding (4.4%), folic acid and vitamin K (5.9%), counseling on general issues (14.7%), and sexuality (4.4%).

Conclusion: Using consensual knowledge lists might promote congruence in educating and/or training community pharmacists on women's issues in epilepsy. Future studies are needed to investigate if such lists can improve health services provided to women with epilepsy (WWE).

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1. Introduction

Epilepsy is one of the most common chronic neurological disorders in which the brain is in enduring predisposition to produce unprovoked and recurrent seizures [1,2]. Typically, epilepsy starts in early childhood or adolescence, and according to recent estimates, the prevalence rate is about 7.60 per 1000 (95% confidence interval 6.17–9.38) [3]. Today, there are more than 65 million people living with epilepsy around the world [4,5].

Despite the fact that epilepsy inflicts women and men equally [6], it is well-established that being a woman with epilepsy can be radically different from being a man with epilepsy. Caring for women with epilepsy (WWE) can be challenged by many gender-related issues [7]. These issues are related to choosing suitable antiepileptic drugs (AEDs) for WWE of childbearing age, teratogenicity, breastfeeding, influence of hormones on seizures, potential interactions between AEDs and contraceptives, sexuality, bone health, and many more [8,9]. Such

issues can present a challenge for both, WWE themselves as well as the healthcare professionals caring for them.

Women with epilepsy represent a considerable portion of all societies. For example in India, there are more than 2.5 million WWE of whom more than half are in the childbearing age group [10,11]. In the US, there are more than 1.3 million WWE in the childbearing age group who give birth to approximately 25,000 newborns each year [12]. Typically, epilepsy requires daily treatment with AEDs on the long term, and this treatment should be continued even in pregnancy. Treating pregnant WWE is particularly challenging because of the teratogenic potential of some AEDs. Exposure to AEDs during pregnancy represents one of the most frequent exposures to teratogens, and infants born to WWE are at an elevated risk of intrauterine growth retardations, cognitive dysfunctions, minor anomalies, major congenital malformations, and infant mortality [12–16].

Modern approaches to managing chronic conditions require patients to choose, self-manage, be in concordance with, and make informed shared decisions with the healthcare professionals caring for them [17,18]. Therefore, provision of information is crucial, especially, when decisions are complicated as in WWE. Providing information to WWE might enable them to recognize the adverse effects of the treatment, alleviate fears, dispel myths and misconceptions, and help them feel in

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control of their own lives [17,19–23]. Unfortunately, studies conducted in the field showed that WWE lack essential information about their disease and/or medications [17,24,25]. In these studies, WWE complained poor provision of information by their healthcare providers and demanded more dialog on women's issues with their caring healthcare providers [26,27]. Among all healthcare providers, community pharmacists are one of the most trusted and easily accessible [8]. Furthermore, patients, including those with epilepsy, reported good relationship with their caring community pharmacists [8,28]. Pharmacists are expected to educate patients about their diseases, on the best ways to use medications, and the importance of adhering to medications; ensure accuracy of doses; explain side effects; screen for and inform physicians about potential drug–drug and drug–food interactions [8,9,29]. Unfortunately, previous studies reported many anecdotes of healthcare professionals including community pharmacists lacking essential knowledge of women's issues in epilepsy [8,9,30–33].

The Knowledge of Women's Issues and Epilepsy II (KOWIE-II) questionnaire which is a valid tool was used to examine knowledge of healthcare professionals of issues related to the health of WWE [8,9,32,33]. The use of this tool showed the existence of many knowledge gaps as healthcare professionals were not adequately informed of women's unique health issues in epilepsy and suggested a need for educational and training interventions to bridge these gaps [8,9,30,31]. Obviously, there is no consensus on what constitutes sufficient knowledge of women's health issues in epilepsy. However, it is indispensable for community pharmacists to possess good knowledge in order to provide quality information to patients and probably their caring physicians. While there were professional groups who often develop guidelines to help physicians care for pregnant WWE [34], community pharmacists were left unguided and the literature does not narrate on what information community pharmacists should have on women issues in epilepsy that should be addressed and ensured during educating and/or training future pharmacists or during continuing educational and/or training interventions for practicing pharmacists. This study was proposed to fill this gap.

This study sought to develop a consensual core list of important knowledge items that community pharmacists should have on women's health issues in epilepsy. This list might serve as a guidance for educators, trainers, and/or authorities for educating and/or training future pharmacists on women's health issues in epilepsy or for designing continuing educational and/or training interventions for practicing community pharmacists.

2. Methods

2.1. Study design and the Delphi technique

In this observational study, a modified Delphi technique was used to achieve consensus among a panel of experts on a series of knowledge items related to women's issues in epilepsy that community pharmacists should know. In this modified Delphi technique, a combination of qualitative and quantitative approaches was used to achieve consensus among the panelists. The Delphi technique has been extensively used in developing concepts and achieving consensus on issues with limited or no formal consensus in healthcare [35–42]. The Delphi technique was appealing because of a number of advantages over other formal consensus techniques. These advantages included convenience in the ability to overcome the geographical barriers in recruiting panelists with prior knowledge of the topic being investigated, cost-effectiveness in overcoming the need to bring the panelists on a round-table meeting or a focused group, ability to preserve the anonymity of the panelists to one another, and overcoming the possibility of one panelist to dominate the discussion as in round-table meetings, nominal, and focused groups [43,44]. The technique makes use of iterative rounds in which panelists make private, independent ratings of agreement or disagreement with a series of statements. Iterative rounds are repeated over an extended

period of time until consensus is achieved [45]. After each round, panelists are fed back with the summary of their own ratings along with the ratings of other panelists and comments they made to justify or qualify their ratings and then are asked if they wished to change or maintain their original ratings in view of the ratings and/or comments of other panelists [35–37]. It is highly likely that achieving consensus among the panelists would require more than one round.

2.2. Interviews and review of the literature

Before conducting the iterative rounds, 9 key contacts (3 neurologists, 2 WWE, and 4 community pharmacists) were interviewed for their views and opinions on what knowledge of women's issues in epilepsy community pharmacists should have. The two WWE were diagnosed since more than 20 years, were married, had children, and believed community pharmacists should play a greater role in caring for WWE. The neurologists often cared for patients with epilepsy including women. The four community pharmacists were practicing in the field and interacted with a large number of WWE. The key contacts were asked to list knowledge items of women's issues in epilepsy that they believed community pharmacists should know. The objective of these interviews was to generate a core list of knowledge items of women's issues in epilepsy that community pharmacists should possess. The knowledge items provided by the key contacts were recorded. An extensive review of the literature was then conducted to identify all potential knowledge items of women's issues in epilepsy that community pharmacists should know [2,8,9,16,26,28,31,33,34,46–135]. All women's issues in epilepsy provided by the key contacts as well as those found in the literature were summarized and formulated into statements and compiled into a questionnaire. The questionnaire was piloted for readability and comprehensibility.

2.3. Ratings and comments from a panel of researchers with interest in women's issues in epilepsy

Before conducting the iterative Delphi rounds among the panel of pharmacists, the questionnaire was sought to be rated and commented by a panel of researchers with interest in women's issues in epilepsy. The objectives of this step were to validate the questionnaire and obtain more potential knowledge items. To identify potential panelists with interest in women's issues in epilepsy, the PubMed database was searched using the advanced search option with MeSH terms like “women” AND “health” AND “epilepsy”. The articles that were judged related to the topic being investigated were collected and searched manually. An email was sent to the corresponding author inviting him/her to be part of the panel to rate and comment on the questionnaire ($n = 15$ corresponding authors). The invitation explained the objectives of the study, and the corresponding author could choose to refer to the author who could better rate and comment on the questionnaire. Respondents were asked to provide their sociodemographic and practice details like gender, age, academic qualifications, specialty, place of work, number of years in practice, number of publications related to epilepsy, and a brief narration of the researchers experience with people with epilepsy. They were also asked to provide their consent to include their names and affiliations in the list of panelists who were consulted. Respondents had the options either to consent to include their names, initials, or remain anonymous. Respondents were requested to provide ratings of their agreement or disagreement on the knowledge items provided in the questionnaire, encouraged to include written comments to qualify or justify their ratings, and suggest more knowledge items that were not included in the originally developed questionnaire.

2.4. Panel of pharmacists

A judgmental sampling technique was used to recruit and compose a panel of pharmacists. Selection of the panelists was based on personal contacts in the field. It is well known that ensuring selection of panelists

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