



Short communication

Support systems of women with epilepsy in pregnancy: A retrospective needs assessment



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ARTICLE INFO

Article history:

Received 21 September 2015

Received in revised form 1 December 2015

Accepted 22 December 2015

Keywords:

Support systems
Women with epilepsy
Pregnancy
Psychosocial stressors
Patient centered care
Qualitative interviews

ABSTRACT

Purpose: To explore support systems for women with epilepsy (WWE) during pregnancy.

Methods: Audio-recorded, transcribed, semi-structured telephone interviews with WWE in pregnancy and following childbirth were coded using descriptive thematic analysis.

Results: Twelve women with epilepsy aged 21–37 years who received care during pregnancy in our epilepsy clinic from 2010 to 2013 were interviewed. Women identified three areas of support: immediate family, their specialist and group support. Some women felt unable to fully share health concerns with family members, but appreciated their support. Neurologists were perceived as reliable sources of support and information, but could be inaccessible. Support groups were seen as beneficial, but may heighten women's fear of epilepsy-related adverse events during pregnancy.

Conclusion: This study highlights the use of support systems by WWE during pregnancy. The richness of the transcribed interviews provides valuable insight into the pregnancy-experience of WWE and helps to direct future clinical and research goals and hypotheses.

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1. Introduction

The experience of women with epilepsy (WWE) during pregnancy have been previously studied [1–3]. One study found that WWE experienced heightened anxiety giving birth as compared to non-epileptic women [1]. Another found that WWE experienced greater external and internal scrutiny, increased stress during pregnancy, and fear of childbirth [3]. To our knowledge, none have focused on the support systems used by WWE in pregnancy. We therefore explored the types of social support utilized by WWE during pregnancy. Patients were also asked to identify strategies that care providers could adopt to improve patient-centred care, outcomes, and patient satisfaction. A better understanding of these factors will contribute to improving patient care.

2. Methods

A convenience sample of epileptic women between the second trimester of pregnancy and within four years post delivery was recruited at Sunnybrook Hospital between September and December 2013. Women were recruited by author J.Q. (research assistant and medical student at the University of Toronto), and were reassured that regardless of whether they chose to participate in the study, their healthcare would not be affected. J.Q. was not involved in patient care. All participants gave consent to participate in qualitative, semi-structured, 30 min, individual telephone interviews with author J.Q. (Supplementary Table 1). These were then audio-recorded and transcribed verbatim. Data were analyzed using the constant comparative method of descriptive data analysis [4], a method for analyzing qualitative data. This iterative process involves breaking down, examining, coding and categorizing data, and comparing different categories with the ultimate goal of generating unifying themes or concepts that help explain a particular phenomenon/experience. Data analysis was performed by authors J.Q., J.N.Y., and E.B. Consensus was reached among all authors. Ethics approval from Sunnybrook Health Sciences Centre Research Ethics Board was obtained.

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<http://dx.doi.org/10.1016/j.seizure.2015.12.017>

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Table 1
Clinical characteristics of study participants.

ID	Age at interview	Age at most recent pregnancy	Age at diagnosis	No. of children	No. of pregnancy	No. of months post delivery at time of interview
1	32	29	8	0	First	48
2	30	29	20	0	Second	3
3	33	31	29	1	Second	18
4	22	21	Unknown	0	Second	2
5	37	36	3	0	First	1
6	36	33	24	0	First	48
7	34	33	24	1	Second	1
8	28	28	Unknown	1	Second	N/A–21 wks gestation
9	29	28	2	0	First	1
10	21	21	5	0	First	N/A–32 wks gestation
11	35	34	18	1	Second	1
12	32	31	28	0	Second	1

Age, number of previous pregnancies, number of children, and time elapsed since most recent pregnancy at the time of interview, are shown for each participant. Although most women (7/12, 58.3%) had had a pregnancy prior to the most recent pregnancy, only a minority of participants successfully completed their first pregnancy (4/12, 33.3%).

3. Results

Twelve epileptic women aged 21–37 years at the time of interview were included. Their average age at pregnancy was 29.5 years (range 21–36 years). For the majority of participants (8/12, 66.7%), this was their first successful pregnancy. Women were an average of 12.4 months post childbirth at the time of interview (range 1–48 months), excluding two participants who were pregnant at the time of interview (Tables 1 and 2).

Three key levels of social support were identified: (1) individual–family, (2) individual–neurologist, and (3) individual–society.

Eight (8/12, 75%) respondents felt increased need for and reliance on family for emotional, financial, and physical support during pregnancy, but disliked behaviours perceived as hyper-vigilant or over reactive from family and friends, as this impacted negatively on their personal independence.

Neurologists were seen as important and credible sources of information and support, and these women preferred to be cared for by their own neurologist in emergencies, even if emergency department physicians were perceived as knowledgeable. More frequent interactions with neurologists, particularly when medical information was provided in concise, lay language, were preferred.

Furthermore, patients appreciated honest and straightforward physician answers, but stressed the importance of delivering them in a sensitive and compassionate manner.

Six (6/12, 50%) women perceived neurologists to be inaccessible and did not expect their neurologists to communicate with them outside of appointments. Any email or telephone contact was therefore appreciated, especially given their physical limitations due to pregnancy and frequent lack of driving privileges. Some also expressed desire for closer involvement of their neurologists in their pregnancy care, especially in the peripartum period, a critical time during which these women felt most vulnerable. Women also emphasized the need for effective communication between their care providers (e.g., between the neurologist and obstetrician/midwife), particularly in the postpartum phase, as medication adjustments were often necessary for effective epilepsy management.

A desire for enhanced communication also extended to include their peers. Seven (7/12, 58%) women agreed that support groups for WWE in pregnancy, where experiences are shared and mutual support offered, would be beneficial for stress relief. This was especially important to those with less established support systems. For example, one participant, who experienced conflict with her in-laws and husband because of her epilepsy, stated that

Table 2
Select quotations from women with epilepsy reflecting on their pregnancy experience.

Quotation number	Quotation	Theme
1.	My husband, and everybody around me was very, very stressed...if I felt that I was going to have...an aura that night, I may not have told him...because...it may not happen, and because...I'm still...a capable human being (Participant 7)	Patient–Family
2.	If I say I feel tired, my family is on edge. I might not be that exhausted that I'm going to trigger one, but everyone gets really nervous around me when I say that. I can't even say that I'm tired. I can't look tired. I can't yawn during the day, because everybody – my husband freaks out (Participant 3)	Patient–Family
3.	Doctors [should give] patients the confidence to not worry so much. I think [my doctor] was calming me down most of the time. So it felt good to have a doctor that could do that instead of freaking you out all the time (Participant 2)	Patient–Doctor
4.	She was so, so, so compassionate. That helped me deal with everything because I was not afraid. I was so positive at that time (Participant 11)	Patient–Doctor
5.	I would have liked if she was actually there [to check up on me] after I gave birth (Participant 4)	Patient–Doctor
6.	It would have been beneficial if you have someone [else] to contact, then that's a big help (Participant 2)	Patient–Doctor
7.	I have a lot of friends right now that are pregnant, but none of them have epilepsy like me, so it's been hard to relate with a lot of people that are pregnant because it's not the same situation by far (Participant 10)	Patient–Group support
8.	Personally, I feel that if the person is pregnant as well, are you going to worry that person with your problems? ...she could get more worried, and I would create more worries (Participant 1)	Patient–Group support
9.	I don't have the energy to add something else to my schedule (Participant 6)	Patient–Group support

she would appreciate the opportunity to express her frustrations among a group of supportive women. Women also felt unable to relate to pregnant women who do not have epilepsy.

Participants perceived support groups to be of greater benefit for women with poorly controlled or newly diagnosed epilepsy. Those who perceived their epilepsy as 'atypical' (e.g., nocturnal seizures only), felt support groups would serve little benefit. Two (2/12, 17%) felt that talking about their illness in a support group would exacerbate their stress and potentially cause more worries for the other women as well.

Support groups were seen as more helpful if members were of similar age to increase the likelihood of common concerns and interests among group members. A support group with semi-structured agendas for discussion would also likely motivate women to attend. Three (3/12, 25%) women noted that discussions on virtual forums, such as Facebook and Skype, in conjunction with in person meetings would offer additional advantages: (1) flexibility in message timing; (2) potential for immediate group feedback, and (3) zero travel time (many women noted that they were usually too tired to travel to a support group).

4. Discussion

We explored WWE's support systems during their pregnancy through qualitative interviews. Three key sources were identified: family, physicians, and support groups. All were important sources of support, but each had their unique limitations.

Several studies have concluded that nurses and other health-care workers, in addition to physicians, can help improve self-management skills of patients with chronic diseases in general [5,6]. Women in our study expressed the need for more interactions with physicians, as well as other healthcare providers specializing in epilepsy care during pregnancy. This illustrates a disparity between patients' ideas of ideal epilepsy care in pregnancy and current care models, highlighting the need for additional 'points of contact' within the healthcare team, especially in the immediate postpartum stage. Interdisciplinary epilepsy care units similar to multidisciplinary, team-based practice seen in other chronic diseases such as diabetes in pregnancy [6] could serve as a model for epilepsy care and increase patient satisfaction among pregnant WWE.

Most women in our study saw a beneficial role for support groups in pregnancy, and emphasized that positive identification with a group was important to ensure maximal benefit. Though support groups existed locally for women with epilepsy, none existed specifically for women with epilepsy during pregnancy. Previous work on support groups in the context of chronic diseases suggests that these groups can meet the psychosocial needs of patients [7]. However, the success of support groups hinges on recognizing the unique profiles of pregnant women with epilepsy, including chronicity of disease, seizure frequency, epilepsy type, and existing support systems. Poorly matched participants may only serve to heighten anxiety and vigilance. For some, support groups may not provide any benefit. Indeed, a study with breast cancer survivors showed that support groups were not likely beneficial to those who avoided illness-related thoughts and emotional expression [8]. Our results suggest that neurologists should be aware of individual variations in coping style and emotion regulation when referring patients to support groups.

The richness of qualitative interviews presented here offers valuable insight into the intricate interpersonal relationships and

unique psychosocial states of pregnant WWE. A limitation of the study is the relatively small sample size. In addition, as most of these interviewed women were Caucasian, married, and lived in an urban environment, and only a few women were second-generation immigrants, our study may not reflect WWE in multicultural populations and rural areas. Another limitation is the retrospective nature of our study. Some women were four years post pregnancy during the interview (Participants 1 and 6), raising the possibility of recall bias.

This early exploratory study helps to fill the knowledge gaps in epilepsy care in pregnancy. Clinicians should be considerate of individual variations in coping styles and aware of the need for increased social support during pregnancy, in order to address it effectively. To this end, team-based practice that incorporates multidisciplinary professionals could offer patients more individualized epilepsy education and more extensive support. Finally, should the findings presented in this study hold true across other populations, the interdisciplinary strategies we recommend here could help shape future clinical practice, inform healthcare policies, and improve patient outcomes.

Conflict of interest statement

None of the authors have any conflict of interest to disclose. We confirm we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Acknowledgements

This research was supported by the Sunnybrook Foundation, Epilepsy Research Fund.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.seizure.2015.12.017>.

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