



## Review

# Women living with epilepsy, experiences of pregnancy and reproductive health: A review of the literature

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## ABSTRACT

**Purpose:** This study aimed to investigate the experiences of pregnancy in women living with epilepsy through a review and synthesis of existing literature.

**Methods:** A comprehensive search of the literature was conducted in medical and social science databases to identify qualitative research, and questionnaires that included open-ended questions, which reported on the impact of epilepsy on the lives of pregnant women from preconception to post-delivery. The search was widened to include qualitative studies on pregnancy and issues of reproduction with women living with chronic illness that had at least one woman with epilepsy in the sample. The systematic search, carried out from April to June 2012, identified 17 publications that met the inclusion criteria, and 24 publications that did not. Qualitative results from these studies were categorised into: stage of pregnancy (preconception, pregnancy, and postnatal); case studies of patients' experiences; and the reproductive health experiences of women living with chronic illness.

**Results:** One qualitative study was identified that directly investigated women's experiences of epilepsy during pregnancy. Many of the findings from the 16 remaining publications were found to be limited in generalisability due to small sample sizes and/or the poor quality of data.

**Conclusion:** Qualitative research on women's experiences of pregnancy whilst living with epilepsy is needed to address this critical gap in knowledge. This paper calls for improved preconception, pregnancy and postnatal supports and information for women living with this condition.

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## 1. Introduction

Epilepsy is one of the commonest neurological disorders affecting an estimated 50 million people around the world,<sup>1</sup> all of whom live with the fact that they could have an epileptic seizure at any time. Women with epilepsy who are of childbearing age face additional challenges as the condition carries with it symptoms and treatment options that have serious implications for their reproductive health. Seizures and antiepileptic drugs (AEDs), the mainstay treatment to prevent seizure recurrence, influence all aspects of women's experiences of having a child: from preconception, pregnancy and labour, to the postnatal stage and infant care.

To date research on epilepsy and pregnancy has been overwhelmingly investigated using quantitative methods, and this is reflected in evidence-based reviews covering the area.<sup>2–4</sup> In

additional expert reviews<sup>5,6</sup> and guidelines<sup>7</sup> on the management of epilepsy in pregnancy focus on aspects of care important to health professionals. However, there is a stark absence of research concerning the priorities and perspectives of patients themselves. A recent systematic review of qualitative studies on the impact of epilepsy on adults and children<sup>8</sup> shows such research has also neglected women's reproductive health issues and experiences. Bagshaw, Crawford and Chappell<sup>9</sup> provide evidence of the need for more extensive and high quality research in this area, which is required to guide practice and improve care for women as they navigate pregnancy and epilepsy.

## 2. Methods

### 2.1. Qualitative literature identification

The two reviewers independently conducted general searches of the literature on epilepsy and pregnancy. The authors brought these materials together to decide upon search criteria terms, appropriate literature databases, and inclusion and exclusion criteria. This initial 'trawl' of the literature revealed much 'self-help' material on the subject of epilepsy and pregnancy. In order to

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remove such works from the review, the search was limited to peer-reviewed literature.

An initial search in February 2012 revealed only one qualitative study, which directly addressed the experiences of pregnancy by women living with epilepsy.<sup>10</sup> In order to capture further insights into women's perspectives on managing their epilepsy whilst being pregnant, the reviewers expanded the search from an exclusive focus on qualitative studies on epilepsy and pregnancy. The search was widened to include: (1) qualitative studies on issues of reproduction and epilepsy; (2) studies using questionnaires with some open-ended questions, i.e. not exclusively quantitative in design; (3) qualitative studies on pregnancy and reproductive issues with women living with chronic illness that included at least one woman with epilepsy in the sample population.

From April to June 2012, a structured search was carried out in the following:

- Health and medical databases: Medline, Cambridge Scientific Abstracts Illumina, CINAHL Plus, Ingenta Connect, and Maternal & Infant Care.
- Social Science and psychology databases: Applied Social Sciences Index & Abstracts, International Bibliography for Social Sciences, PsychArticles & PsychoInfo, and the Social Science Citation Index.

See Fig. 1 for a chart of search terms and the combinations employed in the databases.

Additional strategies were used to identify recently published articles that may not have been located through databases. The search was kept 'live' through Zetoc Alert until August 2012. The Cochrane Library was searched for any recent systematic reviews on the subject that could provide a source of additional references. A manual check of the bibliographies of all the accepted studies and of recent reviews was performed to supplement the search and to ensure that the literature retrieval process was thorough and complete.

## 2.2. Literature selection

The eligibility of literature was determined by the two reviewers. Both reviewers screened the 17 eligible and 24 non-eligible publications identified. Literature exclusion criteria included:

- Non peer-reviewed literature
- Non-human studies
- Languages other than English
- Literature Reviews

Results were imported into Endnote X5 software and checked for duplication. Abstracts of publications that were identified were screened to locate primary qualitative research, and questionnaires employing some open-ended questions on pregnancy and reproduction issues amongst women living with epilepsy. For further details on the methods used for this review, please contact the authors.

## 2.3. Literature analysis

Results from these studies were grouped and analysed into the following categories: the stages of pregnancy (preconception, pregnancy, and postnatal); case studies of patients' experiences of epilepsy and pregnancy; and the reproductive health experiences of women living with chronic illness and/or disabilities.

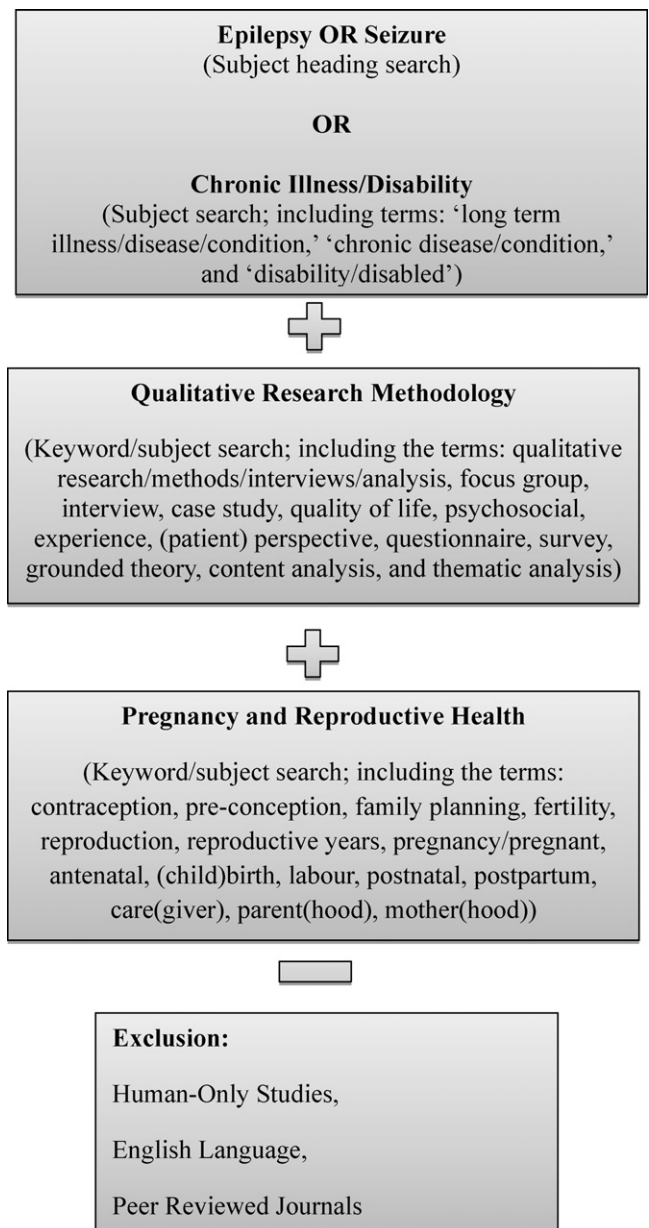


Fig. 1. Chart of search term combinations and exclusion criteria employed in the review of literature.

## 3. Results

### 3.1. Literature search and review

See Table 1 for details of the reviewed literature, including author(s), year of publication, country, sample, study objective, and methodology/analysis.

### 3.2. Preconception: counselling, information access, genetics and reproductive choices

#### 3.2.1. Preconception counselling

A search of the literature revealed relatively few qualitative data studies on the preconception experiences and needs of women living with epilepsy, with the exception of Thompson et al.'s study.<sup>10</sup> To date, this research has focused primarily on preconception counselling interventions<sup>11</sup> and access to information regarding pregnancy and epilepsy prior to conception.<sup>12,13</sup>

**Table 1**

Search results: women's experiences of epilepsy, pregnancy and reproductive health.

Author(s), year	Country	Sample	Study objectives	Methodology/analysis
Corbin, 1987	US	N=20 Aged 21–38 years Pregnant women with chronic illness (one with epilepsy)	Understand the strategies that chronically ill pregnant women use to increase their chances of having a healthy baby	Interviews (longitudinal, in-depth); Grounded theory analysis
Crawford and Hudson, 2003	UK	N=2000 Aged 19 years and older Female members of Epilepsy Action	Assess the quality of current treatment information provision to women with epilepsy at different life stages; identify information needs of women	Postal questionnaire
Crawford and Lee, 1999	UK	N=1855 Female members of the British Epilepsy Association	Examine issues relating to women's management of epilepsy	Postal questionnaire
Larner, 2009	UK	N=1 Anglo-Welsh writer Margiad Evans (1909–1958) with epilepsy	Summarise Evans's autobiographical writings on epilepsy	Case study; Qualitatively examined writings
McAuley et al., 2012	US	N=21 Mean age of 27.5 years Women with epilepsy in their 2nd or 3rd trimester of pregnancy	Understand why some women with epilepsy stop or decrease their AED therapy during pregnancy	Focus groups; Thematic analysis
Morrison, Thomas and Smith, 2012	UK	N=1 Nicola Morrison, who has juvenile myoclonic epilepsy and has had two pregnancies	Tell a patient's life-history with epilepsy in her own words	Case study
Neaves, 2008	UK	N=1 Woman with epilepsy (frequent atonic seizures) and learning disabilities whose children were taken into care	Reflect on a community placement to identify support needs of parents with learning disabilities	Case study
Pashley and O'Dono-ghue, 2009	UK	N=15 Aged 20–39 years Women with epilepsy who conceived between 2001 and 2005	Explore why some women with epilepsy become pregnant without receiving preconception counselling	Interviews (open-ended questions); Thematic analysis
Shostak, Zarhin and Ottman, 2011	US	N=40 Men and women with epilepsy (22) Family members (18)	Capture the perspectives on genetic testing held by people with epilepsy and their family members	Interviews (in-depth)
Thomas, C., 1997	UK	N=17 Women with 'disabilities' (one with epilepsy) who are considering having children, are pregnant, or have had children	Explore the experiences of childbearing and motherhood by women living with disabilities	Interviews (in-depth)
Thomas, C. and Curtis, 1997	UK	N=17 Women with 'disabilities' (one with epilepsy) who are considering having children, are pregnant, or have had children	Explore social barriers faced by disabled women considering having a baby, use maternity and related services and become mothers	Interviews (in-depth)
Thomas, H., 2003	UK	N=15 Women with serious illnesses (one with epilepsy) existing prior to, or developing during, pregnancy	Explore the experiences of women living with serious illness during their pregnancies	Interviews (in-depth); Multiple careers analysis
Thomas, H., 2004	UK	N=15 Women with serious illnesses (one with epilepsy) existing prior to, or developing during, pregnancy	Understand the postnatal experiences of women who experienced a serious illness during pregnancy	Interviews (in-depth); Thematic analysis
Thompson et al., 2008	UK	N=15 Aged 20–40 years Women with epilepsy; range of neurological symptoms and diagnostic categories; 10 had at least 1 child	Explore the experiences of health care services at key phases of reproduction by women with epilepsy	'Exploratory Qualitative Study' using interviews (in-depth)
Turner et al., 2008	Italy	N=100 Aged 18 years and older Pregnant women with epilepsy (50) Pregnant women without epilepsy (50)	Investigate the prevalence of fear of childbirth in women with epilepsy compared to women without epilepsy	Questionnaire, one open-ended question, and a clinical interview
Walsh-Gallagher et al., 2012	Ireland	N=17 Aged 17–40 years Pregnant women with disabilities (4 with status epilepticus)	Discover the meanings that pregnant women with disabilities ascribe to their pregnancy, child-birth and motherhood experiences	Interviews (in-depth, semi-structured); Phenomenological approach
Widnes, Schjøtt and Granas, 2012	Norway	N=10 Aged 22–39 years Pregnant women with epilepsy taking AEDs	Explore risk perception and medicines information needs of pregnant women with epilepsy	Interviews (in-depth)

Thompson et al.<sup>10</sup> provide insights into women's perspectives of pre-conceptual care and preparation for pregnancy. In their accounts women drew attention to the 'dissonance between specialist advice' and women's own 'internalisation of health messages' advising against taking *any* medication or drugs during pregnancy<sup>10</sup> (p. 59). Thus, women may have to come to terms with this counter-intuitive knowledge that they must continue taking their AEDs to reduce risk. Such realisations did not always come through the advice of healthcare practitioners, but sometimes through women's own past experiences of pregnancy.<sup>10</sup>

Pashley and O'Donoghue<sup>11</sup> found women with planned pregnancies were more likely to seek out information, perceive the teratogenesis risks as more threatening, and more proactively seek a 'safe pregnancy.' In contrast, women with unplanned pregnancies appeared less threatened by teratogenesis risks, experienced more social disadvantage, were more likely to have misunderstandings about epilepsy and pregnancy and were more vulnerable to inadequate primary care epilepsy management. However, the generalisability of the study's findings is limited as it is based on a small sample size of 15 women in one community in the East Midlands, England. The authors' focus on why some women with epilepsy have unplanned pregnancies also risks inadvertently demonising this group of patients. Women become pregnant without prior formal preconception planning for a range of reasons, including the possibility that their AEDs weakened the effectiveness of their oral contraception. It has been shown repeatedly that women do not always receive this vital information regarding drug interaction between AEDs and contraception.<sup>10,12,14,15</sup>

However, a study of female members of the British Epilepsy Association, which is more nationally representative, revealed that those who planned their pregnancies had sought out and received the greatest amount of advice.<sup>12</sup> Pashley and O'Donoghue conclude that successful preconception counselling for women living with epilepsy is determined by a combination of factors including adequate access to care and 'the attitudes and social context of women'<sup>11</sup> (p. 153). The authors recommend preconception counselling interventions to better identify and reach out to women who are more likely to have unplanned pregnancies and to provide more tailored counselling services to this often marginalised group.

The limited and inconclusive data on the preconception period for women living with epilepsy has focused on the effectiveness of counselling interventions.<sup>16</sup> Winterbottom et al.'s systematic review of evaluations of preconception counselling reveals that there is a need for better quality research in this area.<sup>16</sup> There is also a need for more enquiries into women's own experiences of navigating the path to becoming pregnant whilst they manage their epilepsy. Such insights are crucial to informing the kinds of preconception counselling services such women require.

### 3.2.2. Accessing information on pregnancy and epilepsy

Larger-scale, nationally representative questionnaires and surveys of the information needs of women with epilepsy at different lifestages also offer insights into the quality and level of access to information prior to pregnancy.<sup>12,13</sup> Fifty-one percent of women between the ages of 16 and 55 stated they had not received any advice about the possible interactions between contraception and AEDs.<sup>12</sup> This absence of counselling is of concern as certain AEDs can decrease the efficacy of some oral contraceptive pills. Women's attempts to control their fertility and avoid unplanned pregnancies are not always supported by effective healthcare practice and advice.<sup>10</sup> Those who do not receive accurate and adequate information, have to cope with various consequences, including drug interactions between their AEDs and oral contraception, unplanned pregnancies, and the termination of unwanted pregnancies.<sup>10</sup>

In regards to pregnancy, 34% of women stated they had not received any advice from any health care professionals.<sup>12</sup> Of those who received advice, the majority obtained information from a hospital specialist, a third from a general practitioner, and just over a quarter from the British Epilepsy Association (now Epilepsy Action). While the majority had received some advice, overall women reported feeling that this information was inadequate.<sup>12</sup>

A 2001–2002 survey<sup>13</sup> conducted with female members of Epilepsy Action, revealed that women in the UK still did not receive important information about their condition and the potential adverse effects of AED treatment. The vast majority of women (87%) who were considering having children reported that they would have liked more information about epilepsy treatment and the possible risks to the unborn child. More than half (57%) of respondents wanted information on the latest data on AEDs and possible birth defects regardless of whether findings from such research remained incomplete.<sup>13</sup> These two surveys<sup>12,13</sup> lack generalisability as the sample population questioned were exclusively members of Epilepsy Action. Such women may be more likely to seek out, and have access to, health information than the general population of women living with epilepsy.

A dearth of accurate information about epilepsy and pregnancy may also potentially deter women from having children or choosing to have fewer children. A third (33%) of women of childbearing age reported that they were considering not having children due to their condition.<sup>13</sup> Unfortunately, this survey did not enquire further into how epilepsy shaped women's reproductive choices. These findings are, however, consistent with a more recent 2010 US-based study that found 34% of participants had fewer children because of their epilepsy.<sup>17</sup> The study found that men and women living with epilepsy who chose to have fewer children cited concerns about the impact of their condition on their ability to care for a child as well as the possibility of having a child with epilepsy.<sup>13</sup>

### 3.2.3. Genetics and reproductive decision-making

One qualitative study on the perceptions of epilepsy, genetics and family reproductive decision-making was identified.<sup>18</sup> The American-based study found that those living with epilepsy, as well as their family members, expressed 'personal theories of inheritance' that emphasised the commonalities between relatives, believing that the risk of passing on epilepsy is shared most between family members with similar physical or personality traits<sup>18</sup> (p. 645). Few people with epilepsy have affected relatives and most types of epilepsy do not follow monogenetic (Medelian) inheritance patterns. Despite the relatively small possibility of genetic inheritance, those with the condition continue to overestimate the risks of passing on epilepsy to their children.<sup>18</sup> Thus, epilepsy as an inherited illness remains a common myth; a myth highlighted by medical sociologists Schneider and Conrad some twenty years ago.<sup>19</sup>

Those living with epilepsy expressed feelings of ambivalence towards genetic testing.<sup>18</sup> Potential benefits of testing included: learning the cause of epilepsy, being better positioned to care for their children if they are at risk, reducing feelings of blame and guilt, providing a sense of control and relieving anxieties for those individuals who test negative. While most reported that they would participate in genetic testing if offered, many expressed serious reservations. Some worried that if genetic information became accessible to employers or life and private health insurers this could lead to increased discrimination and stigma for people living with epilepsy and their children. Of greatest concern was how genetic testing and information could significantly alter people's pre-testing reproductive plans and choices – potentially leading to some feeling pressure not to have biological children or to practice selective abortions. In relation to the concern that

testing could greatly alter the concept of 'what epilepsy is,' one participant repeatedly stated, 'you can live with epilepsy'<sup>18</sup> (p. 651), indicating that a genetic test is an unreliable basis for reproductive decision making.

Findings from this American study must be understood within the US privatised health care context. Two issues may suggest that perceptions of genetic testing may not elicit the same response in countries with universal healthcare. Firstly, people in the US have a greater concern of being discriminated against within the health insurance market. However, there is some evidence in the UK that people may also be refused different types of insurance on the grounds of epilepsy.<sup>20</sup> Secondly, there has been a proliferation of private companies offering direct-to consumer genetic testing in the US, increasing the accessibility of such tests even though there are doubts about their accuracy.<sup>21</sup>

### 3.3. *Pregnancy, childbirth and reproductive health care*

The literature search located one study investigating women's experiences of being pregnant whilst managing epilepsy<sup>10</sup> and two additional qualitative studies which focused on pregnant women's management of, and concerns regarding, AEDs.<sup>22,23</sup> Thompson et al.<sup>10</sup> conducted an 'exploratory qualitative' study investigating women's experiences of health care services at key phases of reproduction, including: contraception, pre-conceptual care, pregnancy, birth and breast-feeding, and parenting and child safety. Women reported mixed experiences of healthcare during these stages. Some felt they had received good care, but others were given inadequate information and offered advice from practitioners only after an event had occurred, so impeding the opportunity to take appropriate preventative action.<sup>10</sup> Specific problems identified by women included: the appropriateness of prescribed medication, concerns about the effects of the medication on the unborn baby, advice about the timing of specialist consultations, conflicting advice from general practitioners and specialists, and poor communication between these health practitioners.

Thompson et al. argue that the management of a chronic illness and reproductive health involves work of a 'moral dimension'<sup>10</sup> (p. 54). While women's experiences of the stages of reproduction ranged widely, the authors found that the 'moral work' entailed in having a baby while living with epilepsy ran throughout these varied accounts. For example, in relation to their pregnancy, the concern with the effects of AEDs on their unborn babies created a conflict for women between being a 'good mother' and being a 'good patient.' Women were engaged in such moral work throughout all stages of their pregnancies and sought to avoid 'questionable decisions and actions that might attract ascriptions of carelessness or deviance'<sup>10</sup> (p. 55). While all women may navigate such a path during pregnancy, those with a chronic condition, such as epilepsy, may face heightened external and internalised scrutiny. Thompson et al.'s study provides a much needed contribution to understandings of how epilepsy influences women's experiences of the various stages of pregnancy and reproduction. However, as it is an exploratory study with a small sample size, findings remain limited in scope.

McAuley et al.<sup>23</sup> conducted focus groups to explore why some women living with epilepsy decide to decrease or stop taking their AEDs during pregnancy. The authors found that 12 of 21 participants reported a change in their medication regimens during their pregnancies. Half of these changes were due to an increase in AED dosages prescribed by health professionals, and half were 'self-altering' women who decreased or stopped taking their medication. Participants' primary concerns about managing epilepsy whilst being pregnant were the safety of drug therapy during pregnancy, potential neonatal complications, labour and delivery issues, and neonatal and postpartum management.<sup>23</sup> The

authors do not specify whether these concerns were more likely to be held by women who decreased or stopped taking their medication as explanation for their decisions to 'self-alter' their drug regimen. The study's findings are limited in generalisability due to the small sample size from one academic medical centre based in Ohio, USA. Further, the ten focus groups were conducted with 21 participants, and thus each focus group was conducted with only two to three participants, and thus making it challenging to generate group discussion.

A recent Norwegian study in 2012 shows that from the perspective of women with epilepsy on AEDs, avoiding seizures by taking their medication during pregnancy outweighed the perceived risks to the foetus.<sup>22</sup> However, dose adjustments during and after pregnancy increased women's perceived risks of teratogenicity and seizures. Women's 'confidence' in using AEDs is credited to good communication with their neurologists who provided adequate medication information<sup>22</sup> (p. 597). The study's sample size of 10 limits the scope of findings. Furthermore, all participants self-report strong medication adherence and thus comparisons could not be made with those who reduce or stop taking medication during pregnancy.

One study that met the expanded search criteria explored whether women with epilepsy were more fearful of childbirth during their pregnancies than women without epilepsy.<sup>24</sup> Those with epilepsy were found to have a significantly higher rate of fear of giving birth than the control group, but this difference in fears dissipated post-delivery.<sup>24</sup> As the study was conducted within a small community population in Italy, the findings are limited in scope.

### 3.4. *Postnatal and mothering experiences of women living with epilepsy*

No publications matching the search criteria were found on the postnatal and mothering experiences of women living with epilepsy. For insights into the perspectives of women living with epilepsy on this post-pregnancy stage, we can look to Thomas's examination of the postnatal experiences of women living with chronic illness,<sup>25</sup> Walsh-Gallagher et al.'s qualitative study of pregnancy and disability<sup>26</sup> and Thompson et al.'s study of how epilepsy impacts upon the various stages of reproduction.<sup>10</sup> These studies found that women received little of the support they felt they required from practitioners.<sup>10,25,26</sup> For example, one woman recounts being pressured by staff to bathe shortly after giving birth, which caused her to faint; about the incident she states '... I was so weak and in shock. ... because of my seizures and the fact it was just after having a baby, ... I thought someone would have to stay with me'<sup>26</sup> (p. 159).

In general, women with chronic illnesses reported feeling 'abandoned' by their health team after giving birth and support for such women's specialised needs were absent or inadequate<sup>25</sup> (p. 83). Those with epilepsy expressed anxieties about how having a seizure might affect the safety of their newly born infants; such concerns were not always addressed through the provision of postnatal support and information.<sup>10</sup> As Thomas notes, the postnatal period does not sit in isolation from other stages of pregnancy, but instead 'follows on' from pregnancy and birth, and therefore is a 'physical and mental state worthy of medical care and attention'<sup>25</sup> (p. 87). Thus, the absence of research on the postnatal phase is troubling and further demonstrates the need for qualitative investigations into the lives and reproductive experiences of women living with epilepsy.

### 3.5. *Case studies: patients' accounts of pregnancy and epilepsy*

Two case studies of women's experiences of pregnancy whilst managing their epilepsy provide accounts from patients'

perspectives.<sup>27,28</sup> Morrison shares her story of living with epilepsy, tracing her experience of having a baby in rural Scotland to her second pregnancy in an urban centre, where she found improved supports and specialist care.<sup>27</sup> Larner's examination of the autobiographical works of the Welsh writer, Margiad Evans (1909–1958) provides one of the first patient accounts of epilepsy and a historical glimpse into the problems the writer faced when she became pregnant.<sup>28</sup> While these two case studies provide much needed data on the perspective of patients, more accounts are required to gain an appreciation of the diversity of the reproductive health experiences and concerns of women living with epilepsy.

Neaves provides a case study of a woman living with epilepsy and a learning disability in the UK who had her children taken into social services care.<sup>29</sup> The woman's story demonstrates how epilepsy must be understood within the socio-economic context of people's lives and is inextricable from other challenges they may face: in this case those hardships included learning disabilities and cycles of poverty and abuse. The article, however, is a reflection piece by the author on her community placement and is not written from the perspective of the client.

### 3.6. *Sociology of chronic illness, disability and women's reproductive health literature*

In the absence of qualitative data on women's experiences of pregnancy and epilepsy, we can glean insights from sociological studies of women's reproductive health in the context of chronic illness and/or disability. Here we include findings from research that has at least one woman living with epilepsy within the study sample.<sup>25,26,30–33</sup> Research on the experiences of pregnancy by women living with longstanding conditions constitutes a very small part of medical sociological work on women and reproduction. As Thomas<sup>30</sup> notes, surprisingly little attention has been paid to the experiences of chronically ill pregnant women within the sub-discipline.

An early work within this small body of research is Corbin's 1987<sup>31</sup> study which explored how women with chronic illness adopted 'protective governing' strategies (i.e. the self-management of medical risk) in order to 'maximize' their chances of giving birth to a healthy baby (p. 320). The central focus on protective governing investigates how women's health strategies relate to risks posed to their babies, and not on women's perspectives in and of themselves. Women's perceptions of medical risk, and the regimens necessary to address these risks, may differ from those of medical professionals who may view women's strategies as 'non-compliant' and adversarial when they do not fit with prescribed regimens.<sup>31</sup> Paradoxically, women who are pregnant and living with chronic illness are expected to *actively* manage their own health and that of their unborn child, while also *passively* complying with their health teams' interventions. As Thomas states, 'patients and pregnant women' are told to both 'take proper responsibility for maintaining their health and managing illness, yet make timely requests for medical help and advice, and comply with treatment regimes'<sup>30</sup> (p. 404).

Thomas' 1997 study found that the major concerns of women with disabilities who had, or were considering having children were being seen as 'irresponsible' for taking risks with their baby's health and their own health by choosing to have a child; 'passing on' an impairment to their child; and doctors prescribing the incorrect dosage of medication.<sup>32</sup> For example, one participant with epilepsy believed her doctor's failure to increase her AED dosage in response to pregnancy-related weight gain caused her to have a seizure that could have jeopardised the health of her and her foetus.

Thomas argues that women's encounters with hegemonic medical discourses of reproductive risk sometimes led to them

restricting their reproductive choices by deciding not to have children, to have fewer children, to be sterilised, or to terminate pregnancies.<sup>32</sup> Thus, She states that for women with disabilities who are mothers, or who are thinking about becoming mothers, 'impairment is not the problem,' but rather it is the social barriers, including medical reproductive risk discourse, which serve to exclude people living with disability<sup>32</sup> (p. 624). Drawing on the same research, C. Thomas and Curtis explore these social barriers further, showing that pregnant women with disabilities had poor access within maternity services, did not have their information needs adequately met, and experienced inappropriate 'help' from health professionals and social care workers.<sup>33</sup>

Fifteen years later, a 2012 study shows some of these social barriers persist for pregnant women with disabilities within maternity care in Ireland.<sup>26</sup> Women reported feeling that professionals viewed them as 'liabilities' and 'high risk.' Further, they felt they were unable make choices and exercise control over their childbirth experiences as services were geared to provide for 'normal' (i.e. non-disabled) pregnant women and not adapted for their particular needs.<sup>26</sup> Despite this lack of inclusive and appropriate maternity care, participants welcomed pregnancy as something that affirmed their 'identity and worth as women and as mothers'<sup>26</sup> (p. 156).

Thomas' research with women managing serious illnesses that existed prior to pregnancy or developed during pregnancy, explores the experiences of these women during and after their pregnancies.<sup>25,30</sup> To better understand women's experiences of pregnancy whilst managing a long-term illness, Thomas argues that pregnancy and illness need to be conceptualised as more than a 'concatenation of contingencies for each other'<sup>30</sup> (p. 383). That is, pregnancy and illness should be considered as separate, but at times co-existent and entwined, 'career' paths. For example, women's experiences of their pregnancies were influenced by the prior and expected course of their illness; and in turn, their perspectives on illness were, in part, configured by the course of their pregnancies.<sup>30</sup> For women with pre-existing conditions, pregnancy transformed their experience of being a patient. While some lost the sense of control and management they had achieved before becoming pregnant, occasionally women experienced pregnancy as having 'beneficial effect[s] on the progress of [their] condition'<sup>30</sup> (p. 404).

For the purposes of this review, a major limitation of the six qualitative studies on reproductive health and chronic illness is that each only contains one woman living with epilepsy in the sample population.<sup>25,26,30–33</sup> Furthermore, the experiences specific to participants with epilepsy are not always distinguished within the publications. Thus, it is not possible to discern which findings are particular to women living with epilepsy from those that are shared by women living with chronic illness in general.

## 4. Discussion

A theme found throughout the literature was the lack of appropriate, timely and quality information for women living with epilepsy when having children and accessing healthcare services. This inadequacy of health information reflects the wider, ongoing trend in the UK of those living with epilepsy desiring to know more about their condition and treatment options.<sup>14</sup> Criticisms of epilepsy health services specific to women include the poor provision of information about the side-effects of AEDs and their effect on oral contraceptive.<sup>14,15</sup> Inadequate information provision may not simply be a failure in practitioner-patient communication. A recent survey of neurologists and neurology residents in the US shows a troubling lack of knowledge about the side effects associated specific AEDs in relation to pregnancy.<sup>34</sup> Patients' own

knowledge of issues related to epilepsy and pregnancy are also low.<sup>35</sup>

A drawback of this review is the authors' restriction to literature published in English, and thus cultural differences and global, geographic variability in the experiences of pregnancy in women living with epilepsy could not be explored. The vast majority of identified literature derives from the US or UK. Epilepsy carries a variety of meanings in different cultural and national contexts; contexts that shape the experiences of those living with the condition. This could not be explored, however, due the lack of qualitative research carried out in non-US or non-UK settings.

Much of the scant literature related to the experiences of epilepsy and pregnancy remains exploratory.<sup>10</sup> It is limited in generalisability due to small, community-specific sample sizes<sup>11,22–24</sup> or populations with higher access to epilepsy information,<sup>12,13</sup> or is based on a small number of patient case studies.<sup>27,28</sup> Some studies are dated,<sup>12,31–33</sup> and predate the introduction of newer AEDs<sup>31</sup> such as Lamotrigine, prescribed in the US and UK just over a decade ago, which pose considerably fewer risks to the foetus. Within the six qualitative studies on reproductive health, chronic illness and disability<sup>25,26,30–33</sup> the perspectives of women living with epilepsy are subsumed under the studies' wider findings on women living with lifelong and serious health conditions in general.

As the literature search was limited to peer-reviewed sources of data, some of the information available on women's experiential knowledge of living with epilepsy and reproduction could not be included in this review. Less conventional sources include Epilepsy Action's 'The Pregnancy Diaries' project,<sup>36</sup> an online forum in which UK members share their personal stories of having a baby. Another example is *Epilepsy in Our Lives: Women Living with Epilepsy* (2008), a collection of stories written by women from across the US, of various ages, about their experiences with epilepsy, including accounts of choosing to have or not to have children.<sup>37</sup> While providing graphic accounts, the perspectives of women contributing to alternative sources of data could not be included in this review as such material does not meet the more academic criteria of peer review.

## 5. Conclusion

Approximately a third of all women of childbearing age with epilepsy consider not having children or having fewer children, due to their condition.<sup>13</sup> Therefore, it is recommended that preconception, pregnancy and postnatal support and information provision be improved to help address this relatively high percentage of women who view their condition as a possible barrier to reproduction. Further research of higher quality is required on women's experiences of pregnancy whilst living with epilepsy to address the gap in knowledge in this area. This research is necessary to inform and improve policies, practice and information provision for women living with the condition as they navigate the stages of pregnancy. Such work will also contribute to the scant qualitative data on women's reproductive health and chronic illness.

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## References

1. WHO. *Epilepsy: key facts*. World Health Organisation; 2012 Available at: <http://www.who.int/mediacentre/factsheets/fs999/en/index.html> [accessed 01.08.2012].
2. Harden CL, Hopp J, Ting TY, Pennell PB, French JA, Hauser WA, et al. Practice parameter update: management issues for women with epilepsy—focus on pregnancy (an evidence-based review): obstetrical complications and change in seizure frequency: report of the Quality Standards Subcommittee and Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology and American Epilepsy Society. *Neurology* 2009;73(July (2)):126–32.
3. Harden CL, Hopp J, Ting TY, Pennell PB, French JA, Hauser WA, et al. Management issues for women with epilepsy—focus on pregnancy (an evidence-based review). I. Obstetrical complications and change in seizure frequency: Report of the Quality Standards Subcommittee and Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology and the American Epilepsy Society. *Epilepsia* 2009;50(May (5)):1229–36.
4. Meador K, Reynolds MW, Crean S, Fahrbach D, Probst C. Pregnancy outcomes in women with epilepsy: a systematic review and meta-analysis of published pregnancy registries and cohorts. *Epilepsy Research* 2008;81(September (1)):1–13.
5. Mawhinney E, Morrow J. Managing epilepsy in pregnancy. *Expert Review of Obstetrics and Gynecology* 2011;6(6):667–80.
6. Tomson T, Hilesmaa V. Epilepsy in pregnancy. *British Medical Journal* 2007;335(7623):769–73.
7. Nunes VD, Sawyer L, Neilson J, Sarri G, Cross JH. Diagnosis and management of the epilepsies in adults and children: summary of updated NICE guidance. *British Medical Journal* 2012;344:e281.
8. Kerr C, Nixon A, Angalakuditi M. The impact of epilepsy on children and adult patients' lives: development of a conceptual model from qualitative literature. *Seizure* 2011;20(December (10)):764–74.
9. Bagshaw J, Crawford P, Chappell B. Problems that mothers' with epilepsy experience when caring for their children. *Seizure* 2008;17(1):42–8.
10. Thompson D, Thomas H, Solomon J, Nashef L, Kendall S. Chronic illness, reproductive health and moral work: women's experiences of epilepsy. *Chronic Illness* 2008;4(1):54–64.
11. Pashley S, O'Donoghue MF. The safety of anti-epileptic drug regimens: a qualitative study of factors determining the success of counselling women before conception. *Journal of Family Planning and Reproductive Health Care* 2009;35(3):153–6.
12. Crawford P, Lee P. Gender difference in management of epilepsy—what women are hearing. *Seizure* 1999;8(3):135–9.
13. Crawford P, Hudson S. Understanding the information needs of women with epilepsy at different lifestages: results of the 'Ideal World' survey. *Seizure* 2003;12(7):502–7.
14. Prinjha S, Chapple A, Herxheimer A, McPherson A. Many people with epilepsy want to know more: a qualitative study. *Family Practice* 2005;22(4):435–41.
15. Wallace HK, Solomon JK. Quality of epilepsy treatment and services: the views of women with epilepsy. *Seizure* 1999;8(2):81–7.
16. Winterbottom JB, Smyth RM, Jacoby A, Baker GA. Preconception counselling for women with epilepsy to reduce adverse pregnancy outcome. *Cochrane Database of Systematic Reviews* 2008;(3):CD006645.
17. Helbig K, Bernhardt B, Conway LJ, Valverde KD, Helbig I, Sperling MR. Genetic risk perception and reproductive decision making among people with epilepsy. *Epilepsia* 2010;51(9):1874–7.
18. Shostak S, Zarhin D, Ottman R. What's at stake? Genetic information from the perspective of people with epilepsy and their family members. *Social Science and Medicine* 2011;73(September (5)):645–54.
19. Schneider JW. *Having Epilepsy: The experience and control of illness*. Philadelphia: Temple U P; 1983.
20. Jacoby K, Jacoby A. Epilepsy and insurance in the UK: an exploratory survey of the experiences of people with epilepsy. *Epilepsy & Behavior* 2004;5(December (6)):884–93.
21. Thrush S, Ruth McCaffrey A. Direct-to-consumer genetic testing: what the nurse practitioner should know. *The Journal of Nurse Practitioners* 2010;6(4):269–73.
22. Widnes SF, Schjott J, Granas AG. Risk perception and medicines information needs in pregnant women with epilepsy—a qualitative study. *Seizure* 2012;21(October (8)):597–602.
23. McAuley JW, Patankar C, Lang C, Prasad M. Evaluating the concerns of pregnant women with epilepsy: a focus group approach. *Epilepsy & Behavior* 2012;24(2):246–8.
24. Turner K, Piazzini A, Franza A, Canger R, Canevini MP, Marconi AM. Do women with epilepsy have more fear of childbirth during pregnancy compared with women without epilepsy? A case-control study. *Birth* 2008;35(2):147–52.
25. Thomas H. Women's postnatal experience following a medically complicated pregnancy. *Health Care for Women International* 2004;25(1):76–87.
26. Walsh-Gallagher D, Sinclair M, Mc Conkey R. The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: a phenomenological understanding. *Midwifery* 2012;28(April (2)):156–62.

27. Morrison N, Thomas R, Smith P. Juvenile myoclonic epilepsy. *British Medical Journal* 2012;**344**:e360.
28. Larner AJ, Evans M, Margiad Evans (1909–1958): a history of epilepsy in a creative writer. *Epilepsy & Behavior* 2009;**16**(4):596–8.
29. Neaves D. Parenting and people with learning disabilities. *Learning Disability Practice* 2008;**11**(8):28–31.
30. Thomas H. Pregnancy, illness and the concept of career. *Sociology of Health & Illness* 2003;**25**(5):383–407.
31. Corbin JM. Women's perceptions and management of a pregnancy complicated by chronic illness. *Health Care for Women International* 1987;**8**(5–6):317–37.
32. Thomas C. The baby and the bath water: disabled women and motherhood in social context. *Sociology of Health & Illness* 1997;**19**(November (5)): 622–43.
33. Thomas C, Curtis P. Having a baby: some disabled women's reproductive experiences. *Midwifery* 1997;**13**(4):202–9.
34. Roberts JI, Metcalfe A, Abdulla F, Wiebe S, Hanson A, Federico P, et al. Neurologists' and neurology residents' knowledge of issues related to pregnancy for women with epilepsy. *Epilepsy & Behavior* 2011;**22**(2):358–63.
35. Metcalfe A, Roberts JI, Abdulla F, Wiebe S, Hanson A, Federico P, et al. Patient knowledge about issues related to pregnancy in epilepsy: a cross-sectional study. *Epilepsy & Behavior* 2012;**24**:65–9.
36. Epilepsy A. The pregnancy diaries: written by mothers to guide you through pregnancy and into early parenthood. *Epilepsy Action* 2012;(July) Available at:<http://www.epilepsy.org.uk/campaigns/women/having-baby/pregnancy-diaries> [accessed 03.04.12].
37. Schachter SC, Krishnamurthy KB, Combs-Cantrell DT. *Epilepsy in our lives: women living with epilepsy*. Oxford, New York: Oxford University Press; 2008.