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The preconception care experiences of women with epilepsy on sodium valproate

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ABSTRACT

Purpose: To understand the preconception experiences of women with epilepsy who have been taking the teratogenic drug valproate.
Methods: Seven women were recruited, three from a preconception clinic and four from an antenatal clinic in a region of the UK. All had taken valproate preconceptionally. Three preconception clinic encounters were observed and audio-recorded. Interviews with all women were analysed using Interpretative Phenomenological Analysis (IPA).
Results: Women experienced a "trajectory of balance". Women moved from "maintaining balance" by using valproate to control seizures, to a "shattering of harmony" at the prospect of changing medication and as a result of the physical and mental effects of changing medication, to "restoring balance" which could involve "a new self" due to dramatic changes. Women balanced their health needs with those of their baby, and took responsibility for medication decision-making. They found it difficult to see "who is looking after me" in the healthcare system, either to access preconception care, or to support them through the stress of changing medication. Their journey ended with coming to terms with a variety of experiences: choosing not to have a baby due to unsuccessful change from valproate, recognising that a child from a previous pregnancy had been harmed by valproate or that the current pregnancy might be at risk, or successful medication change in preparation for pregnancy.
Conclusion: A clear and adequately funded preconception care pathway is needed from epilepsy diagnosis, including support for stress. Understanding what influences maternalisation may help understand uptake of preconception care.

1. Introduction

Preconception care is advocated for women with epilepsy on antiepileptic drugs (AEDs) to enable them to prepare for pregnancy by optimising their general health, and modifying medication to optimise seizure control and reduce the risk of fetal malformation [1,2,3]. For women on valproate, preconception care is especially important, since both risk of structural malformation and neuro-developmental delay are particularly high [4,5,6]. The European Medicines Agency and the Medicines and Healthcare products Regulatory Agency (MHRA) have reinforced recommendations to ensure that "valproate should not be prescribed to female children, female adolescents, women of childbearing potential or pregnant women unless other treatments are ineffective or not tolerated" and recommend that the benefits and risks of valproate should be balanced at a number of key points, including "when a woman plans a pregnancy or becomes pregnant" [7,8]. The most recent development in the UK is that "valproate must no longer be prescribed to women or girls of childbearing potential unless they are on the pregnancy prevention programme" [9,10].

The uptake of preconception care by women with epilepsy has been shown to be influenced by previous pregnancy experiences, attitude to a child with a disability [11] and the relationship that the woman has with her health care provider [11,12,13]. However, surveys of women with epilepsy have shown that few have preconception care, remember having it, or recognise that they had it [14,15,16]. There is a paucity of research about the effectiveness of preconception counselling, a component of preconception care [17] and scant research on the experiences of women with epilepsy in pregnancy [18]. There is thus a thin evidence base for the delivery of preconception care for women on valproate.

We describe here a qualitative study of the preconception care experiences of women with epilepsy on valproate, including their communication with healthcare professionals, decision making

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regarding their medication options and the impact that preconception care had on their lives and preparations for pregnancy.

2. Methods

A qualitative study based on Interpretative Phenomenological Analysis methodology was conducted in a region of the UK between 2014 and 2015 to explore the preconception experiences of women with epilepsy on valproate as part of a larger study of preconception experiences of women with epilepsy. In addition, observational data were collected regarding preconception clinic encounters.

Women were recruited from a preconception clinic (for women planning a pregnancy) and a Joint Obstetric Neurology Antenatal Clinic (for women already pregnant). The preconception clinic runs parallel to a busy seizure clinic which is facilitated by a Consultant Neurologist (Epilepsy specialist) and Epilepsy Specialist Nurses and offers one-to-one counselling to women for women with epilepsy who are contemplating pregnancy whether or not they are taking AEDs. The antenatal clinic provides specialist antenatal care for women with epilepsy who are pregnant and antenatal care is shared with the woman's General Practitioner. At the clinic, care is provided by a Consultant Neurologist (Epilepsy Specialist), a Consultant Obstetrician and Epilepsy Specialist Nurses. Both clinics are the recognised specialist clinics for a population of approximately 25,000 annual births, although women with epilepsy may also be offered informal or formal preconception or antenatal care from neurologists or other healthcare professionals elsewhere.

A purposive sample of non-pregnant women with epilepsy currently taking valproate or who had already changed from valproate for pregnancy were recruited over a six month period at their first preconception clinic appointment (n = 3, of whom 2 were still taking valproate). A purposive sample of pregnant women with epilepsy who were currently taking or who had changed from valproate in advance of pregnancy were recruited from the antenatal clinic at their booking appointment in the first trimester (n = 4, of whom three were still taking valproate). One of these women had attended the preconception clinic prior to pregnancy.

No eligible women declined participation in the study in either of the groups, so that the study sample proved to be representative of the 6 month recruitment period in both numbers and characteristics of the women. However, the sample is small.

Women at the preconception clinic were asked to undertake an interview within three weeks after the clinic, and again at six monthly intervals while not pregnant. Five interviews with three participants took place in the women's home between ten days and one year after the preconception clinic consultation, with the timing determined by the woman and her personal circumstances. Women recruited from the antenatal clinic were interviewed once, at the woman's home, before 24 weeks gestation according to the woman's availability.

The semi-structured interview schedules focused on how women felt about becoming a mother, communication with Health Care Professionals, views and reflection on medication, and medication and decision making. Interviews took between 23 min and 1 h for women pre-pregnancy, and between 22 min and 46 min for women antenatally.

Preconception clinic consultations (n = 3) were audio-recorded and transcribed and data extracted (Appendix A). For the purposes of this paper, brief summary characteristics are described.

Interviews were audio-recorded and transcribed (by LL). Interviews were treated as one data set with three stages of analysis within an IPA framework. In stage one, the interviews relating to each women were analysed by making initial notes and developing themes within each individual case. In stage two, themes were developed across cases starting with the women who had attended the preconception clinic. In stage three, an interpretation of the experiences of all the women was developed resulting in a master theme and lower order themes. In accordance with the process described by Smith et al. [19] consensus was obtained and appropriateness and confirmation of themes determined by returning to the transcripts. The interpretation (themes, illustrated by quotes) was presented to the clinical supervisor (JM) and epilepsy clinicians to determine resonance with clinical experience.

Validity checks of the accuracy of transcripts, and the thematic interpretation, involved three members of the research team (LL, MS, HD).

The study was approved by ORECNI (13/NI/0173) and Trust Research Governance (13107HD-SW). Women were informed in the patient information leaflet that the research team included a clinician from the preconception clinic who was excluded from data analysis until after data interpretation. Women have been given pseudonyms for confidentiality.

3. Results

3.1. Brief description of preconception clinic consultations

The three preconception clinic consultations involved the women, an accompanying person (one mother, one partner, one unaccompanied), a consultant neurologist, and an Epilepsy Specialist Nurse (ESN). Consultations lasted between 32 and 50 min in total, including between 7 and 15 min with the Consultant Neurologist present. The consultations reviewed the woman's personal anti-epileptic drug history, and the options for changing from valproate to another drug. Women were given quantitative information about risk of a major malformation with valproate and how this increases with dose and conversely the chance of having a healthy baby. Women were given the most up to date information about risks related to alternative medications, and uncertainty about these risks using information from the United Kingdom and Ireland Epilepsy and Pregnancy Register (UKIEPR). The UKIEPR is a prospective, observational, registration and follow up study [4] which collects physical outcomes such as major congenital malformations and coordinates with other research groups regarding neurodevelopmental outcomes.

The Clinicians emphasised the importance of women taking time after the clinic appointment to consider their decision. One woman, having had a previous unsuccessful attempt to change from valproate, had already contemplated her options before attending the clinic and expressed her decision to change from valproate during her consultation. Discussion also included topics raised by the women such as medication and fertility concerns (n = 1), concern about their child developing epilepsy (n = 1), and non-medication treatment options (n = 1).

3.2. Participant profile, medication and preconception care history

The women ranged in age from 18 to 38 with six of the women prescribed valproate from diagnosis either in early childhood, adolescence or mid adult hood, and one woman prescribed valproate on transition from paediatric to adult care. Of the seven women, four were allergic to lamotrigine. Of these four women, two had tried lamotrigine prior to pregnancy planning – one at diagnosis and one as part of seizure management – and two had tried lamotrigine as part of pregnancy planning. Of the three women from the preconception clinic, one attended after a successful switch from valproate to lacosamide following a pregnancy on valproate, with concerns about her child and worsening seizure control. Another attended after two unsuccessful attempts to change from valproate onto levetiracetam (mood