



# 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.

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## 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 neurodevelopmental 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 woman 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

swings) and lamotrigine (allergy). The third woman had not yet tried to switch medication. These three women were aware of the risks of valproate from their own neurologist either as part of ongoing care or as advised at the time of commencement on valproate at diagnosis after trying lamotrigine first (allergic). Of the four women from the antenatal clinic, two had received preconception care during which the women had been advised of the risks of valproate. One of these women had attended the preconception clinic following two pregnancy losses which she attributed to valproate and had changed to levetiracetam before her pregnancy. The other had preconception counselling from her Consultant Neurologist prior to her first pregnancy but none prior to her current pregnancy and was still taking valproate. The remaining two women, who were taking valproate while pregnant, reported no preconception care. These women either had a vague or inaccurate awareness of the risks. Neither of these women were having specialist care for their epilepsy.

### 3.3. Interviews

The master theme identified was “A Trajectory of Balance”. It encompasses the drive to maintain balance physically and emotionally and the challenges to achieving balance posed by considering or actualising a change of medication in advance of pregnancy, experienced as a “shattering of harmony”, and the restoration of balance (Table 1).

Before considering pregnancy, the woman describes “balancing myself”. Valproate keeps her epilepsy under control. Women regard their life with epilepsy as normal and there is a desire to achieve the things that women without epilepsy achieve, including motherhood. Women act to maintain balance by not taking a perceived risk with their medication.

As women move towards motherhood, balancing also incorporates balancing their own health against their baby’s health—they describe the to and fro of deliberating and weighing up threats to personal health versus risks to baby’s health. They recognise that changing medication or maintaining the status quo is their decision, and a great responsibility. As women move towards motherhood, their perception of risks change and the known risks themselves change, sometimes between pregnancies. Loss of seizure control is perceived as the greatest risk following a successful switch from valproate.

Women reach out for support to enable them to maintain balance. For some there is uncertainty about who provides the healthcare that is needed in relation to preparing for pregnancy, and how to access it. Some experience inconsistency in the provision, nature and pathway of care and the communication between care providers. Several

women (Bethan, Fiona: Table 2) described a serious effect on their mental health from changing medication away from valproate, but no specific monitoring was in place in relation to this. Women described how their family kept them safe during instability and were understood as acting as a safety net.

The preconception experience was described as a shattering of harmony, upsetting the balance that the woman had been striving to maintain. Changing medication is seen as pulling away their stabiliser, a source of physical and emotional upset. Women with children who were exposed to valproate in a previous pregnancy (Anna, Daphne, Table 2) were being confronted with actual harm and this had a destabilising effect on them. Women were living through a state of uncertainty. Their previous reluctance to take a risk may change when approaching pregnancy and they realise they need to take a risk in order to achieve a better balance between their own health and their baby’s health. Uncertainty is mirrored by hopefulness in the face of uncertainty – hopefulness that the new medication will work, or hopefulness that the outcome of pregnancy will be good.

Balance is restored after everything that has gone before. Reflecting on what has happened, women make an assessment of their current status. For one woman (Bethan: Table 2) her unsuccessful experience of changing medication meant that she had to stay on valproate, and decided not to start a family until new medication options become available – she described coming to terms with this. Diana (Table 2) had experienced a very positive effect on her mental functioning after changing from valproate, and was enjoying her “new self”. Anna (Table 2) was coming to terms with the fact that her child from a previous pregnancy had autism due to valproate exposure, and his special needs. Daphne (Table 2), whose child from a previous pregnancy was also affected, was coming to realise that perhaps if she had changed medication to a less effective one, her child might also have been harmed by her seizures. Three of the women (Fiona, Anna, Daphne: Table 2) described being in a much clearer mental state since switching medication, and were pleased with their “new self”. Fiona (Table 2) was coming to think that her previous miscarriages while on valproate might have been for the best, since she had been exhausted while on valproate. Anna (Table 2) was positive that the difficulties of changing medication were coming to an end and she was getting back to doing what she used to do before valproate; the woman she is now is not the person she was before, her experience has changed her; balance is restored in a different context than at the beginning of the journey.

## 4. Discussion

We have conceptualised the women’s experience as a “Trajectory of Balance” in which preconception care and the

**Table 1**  
Summary of themes.

Master theme: A Trajectory of balance		
<i>Balancing myself</i>	<i>Balancing as a woman with epilepsy</i>	<i>My medication keeps me under control (n = 7)</i> <i>I just take my life as a normal life (n = 6)</i> <i>I don't take a risk (n = 5)</i>
	<i>Balancing as I move towards motherhood</i>	<i>I balance my health with my baby's health (n = 7)</i> <i>I decide (n = 7)</i> <i>Changing perception of risk (n = 6)</i>
	<i>I have to reach for support to steady me</i>	<i>Who's looking after me? (n = 7)</i> <i>Care is not consistent (n = 5)</i> <i>My family is my safety net (n = 4)</i>
<i>Shattering my harmony</i>	<i>Pulling away my stabiliser (n = 4)</i>	<i>Taking a risk (n = 6)</i>
	<i>Realising my child has been harmed (n = 2)</i>	<i>Being hopeful (n = 6)</i>
	<i>Living through a state of uncertainty</i>	<i>Coming to terms with where I am now (n = 7)</i>
<i>Restoring balance</i>		<i>Comfortable with change (n = 4)</i>
		<i>A new self (n = 4)</i>

**Table 2**  
Themes.**A TRAJECTORY OF BALANCE****BALANCING MYSELF****BALANCING AS A WOMAN WITH EPILEPSY****My medication keeps me under control**

*Epilim's my life it was my life it was my drug (Anna PC)*

*epilim chrono was the best medication for me all my life . . . (Bethan PC)*

*I didn't mind being on drugs..as long as it was controlled..to control my epilepsy at the time (Diana PC).*

*I am happy in myself that I am on that drug [valproate] because it is controlling me and because of the fact that I was so well the last time [in her previous pregnancy] (Daphne AN)*

**I just take my life as a normal life**

*I wanted a baby . . . like every maternal mother . . . I wanted a baby (Anna PC)*

*Don't let epilepsy stop you from having a life . . . my granny always said to me 'don't let that stop you cause you can have a life..it's the way the circle of life is, just go ahead and go with it' . . . that's the way I would think (Bethan PC)*

*I'm not worried about epilepsy it doesn't get to me or anything . . . I just take my life as a normal life and that's it . . . it doesn't worry me the way it would some people . . . I just get on with my life . . . (Kirsty AN)*

**I don't take a risk**

*There was a stage that they did talk about changing the drug . . . because of the side effects of the epilim but then I wasn't keen and neither were any of my family because it had taken me so long to get controlled on the epilim . . . so we just went along with it because I was so well (Daphne AN)*

*At that time I wasn't pregnant . . . I wasn't married at that point . . . it wasn't a reality for me at that time and even though I had all those things explained to me I was just thinking why . . . go through having to not drive and the implications that would have for my work and then also maybe I was scared to come off the epilim because it was controlling my condition . . . I was just fearful of the consequences of coming off it..I was thinking it could end up nearly worse so it was hard to make that decision (Fiona AN)*

**BALANCING AS I MOVE TOWARDS MOTHERHOOD****I balance my health with my baby's health**

*I really wanted another baby but I also . . . really wanted to be seizure free and the two things were going together and it was hard! (Anna PC)*

*[the Epilepsy Specialist Nurse - ESN] was explaining to me about the epilim chrono what it can do to the child . . . I don't want to feel selfish and now I know what it can do to the child and it can give the wee baby a disability I thought "naw . . . I don't want to . . . be selfish and bring a disabled child into this environment so I won't. If I hadn't have known . . . I wouldn't have cared.. I would love my child disabled or healthy no matter what . . . but now I know I wouldn't do that on the child . . . (Bethan PC)*

*we went through the risks involved about spina bifida . . . and developmental delay . . . but also balancing that against me coming off medication which had fully controlled it well . . . I did feel as if I had the information but it was just me trying to balance in my own head and justify changing it because it was such a big step (Fiona AN)*

*I was that used to the epilim and when they said to me that I would have to come off them it frightened me a bit because I was thinking oh well I might take a fit when I'm coming off them but I'm just thinking of the child that's in my interest . . . (Isabel AN)*

**I decide**

*I was scared because they didn't know anything about vimpat ..they have no studies on it they have no research they have very little... only . . . animal studies not with my . . . combination . . . they said "we need to get you off this epilim because we know the epilim is not a good drug for pregnancy and the vimpat we don't know anything about because it's a new drug" so it was a big decision . . . (Anna PC)*

*I wanted to change my medication and . . . I was hoping that [the ESN] or the Dr would turn round and say that there's a choice you can change your medication and I was thinking in my head that if they didn't ask that then I would have asked "is there any chance to change my medication" but they said "there's a chance" and I was all "hallelujah" in my head (laughing) and I said yes please if it's best for myself and for the baby (Bethan PC)*

*It took me so long to get controlled on the epilim that we decided against that [changing medication] . . . so we just went along with it and because I was so well and kept so well we just went along with it (Daphne AN)*

*I came to a decision that I would try and change my medication at that point . . . I didn't know whether definitively they had caused the miscarriage ..but I didn't want to wait to find out (Fiona AN)*

*[the clinicians at the PC] haven't sort of imposed things . . . but in some ways that's harder too because if a Dr was telling you "look.. you have to come off this" and you know . . . in some ways that's easier because the decision is took out of your hands but . . . you know they gave you the information they don't sort of dress it up they tell you the facts and figures and I suppose you know you just try and think about it to try and make a good decision (Fiona AN)*

**Changing perception of risk**

*I cannot take the risk . . . definitely not..living with my son and looking after him . . . I have been nearly two years seizure free and I cannot take one chance . . . 10 years taking seizures no I would never take a risk (Anna PC)*

*I'd like to come off that epilim for good but it's just the risk factor at the minute because . . . in one way I'd like to come off them but I wouldn't want to put my work colleagues in a position that they'd have to see me like that (Diana PC)*

*Pregnancy alters Fiona's perception of the risks of valproate: It's alright talking to someone whenever these things are not a reality because it's like saying to a smoker "smoking's bad for you" but when it's a reality and you're taking the tablet every day and you're pregnant and you're thinking "well I hope this is alright . . . I hope I'm one of the lucky percentages" so it was a bit worrying but at the same time you're thinking "if I change the other medication might not be as good" because you learn to trust the medication that you're on (Fiona AN)*

*Fiona talking about her experience after two miscarriages whilst taking valproate: We decided that we would go and talk to Dr B and the ESN . . . about it and just tell them how we were feeling about things because I think . . . there had been a shift in terms of my attitude as well because..I can't keep on doing this and maybe this is telling me something..maybe I shouldn't be on this medication and maybe I should be trying something but before I was always a bit anxious about doing that because I worried about the effects of it and worried that it was going to destabilise me (Fiona AN)*

**I HAVE TO REACH FOR SUPPORT TO STEADY ME****Who's looking after me?**

*They were keeping a close eye on me..I could phone [the ESN] whenever I was feeling scared or anxious..in the back of your head it's always there..as long as people are beside you and you know it will work out.. (Anna PC)*

*I had to contact the ESN straight away and I said to my mum "can you contact the ESN . . . I want to talk to her about having babies" (Bethan PC)*

*I spoke to my . . . GP and he wasn't very helpful (laughs) . . . this has been going on for the last 2 years... how do you go about it? . . . I know because I took the interest in knowing but maybe not everybody because I remembered what the consultant neurologist had said . . . I would have loved to start a family a couple of years ago . . . well my GP never told me anything about it (Diana PC)*

*Fiona talking about her experiences when changing medication from valproate:*

*I was going to see my GP regularly while I was off sick and she knew the side effects that I was having she saw for herself..she wouldn't have interfered too much in terms of the epilepsy because she knew I was seeing [the consultant neurologist] and that was his area . . . from her point of view she was looking at me from how am I managing day-to-day (Fiona AN)*

*At the antenatal clinic they were very nice people and they really did help me out . . . I got more information out of them than what I did from my own Doctors..they told me everything about the medicine and the epilepsy (Kirsty AN)*

**Care is not consistent**

*. . . my mental health . . . it is on the records . . . the consultant neurologist was glad and he said "thank god she was in straight away . . . you know what we are going to have to change your medication back . . . we are going to change your medication but it's not going to be quick and it will take time.." (Bethan PC)*

**Table 2** (Continued)

A TRAJECTORY OF BALANCE
<b>BALANCING MYSELF</b>
<i>I have the contraceptive bar in and I wanted to speak to them [GP] about how long it would take to regulate my body and things like that and I went in and said that I was changing from epilim to keppra and she said "What! Are you seeing someone else about this?" And I said "yes" and she said "that's good because I don't know anything about it" (Diana PC)</i>
<i>... I felt quite annoyed ... because sometimes our Drs don't have a clue what they're on about ... this girl [locum GP] I went and seen first before I seen my own Dr ... she never had a clue ... I was quite annoyed with her ... she told me a load of nonsense like your epilim shouldn't affect your baby (Kirsty AN)</i>
<b>My family is my safety net</b>
<b>When changing medication from valproate:</b>
<i>I kept myself very ... close to my mother ... I didn't know what way it would turn.. I was scared yes I was scared ... I didn't have any seizures but I didn't know if I would ... my mum did stay by me quite a bit for support ... for safety with my son as well ... to reassure me [Anna PC]</i>
<i>My mum said "maybe you're best not having a baby" ... she was worried for me and she said "right we're going to have to see a Doctor and see what is best for your health" (Bethan PC)</i>
<b>When changing medication and admitted to the mental health unit:</b>
<i>One night I was out with my friends and the day after I came out of the house ... my step-father was driving up in the car and I came up crying to him "I'm depressed I'm depressed" ... and he knew there was something wrong and he got the phone and Dr [consultant neurologist] was glad we phoned him straight away when I was in [the mental health unit] (Bethan PC)</i>
<i>I think my mum nearly worried more than I did ... she came with me to every hospital appointment ... and she asked the Dr on a number of occasions would there be any possibility that I would have a seizure during labour or would it affect the baby in any way (Daphne AN)</i>
<b>SHATTERING MY HARMONY</b>
<b>PULLING AWAY MY STABILISER</b>
<i>It was the ESN's idea and Dr B ... get me off this epilim ... and I had been on it for such a long time from when I was 14 so that was scary ... and I thought "no I can't do this!" (Anna PC)</i>
<b>Bethan during her most recent change from valproate:</b>
<i>I was banging my head here (points to radiator) and I just wasn't right just wasn't myself ... I can remember what I was doing and I couldn't speak and hear ... I feel like I felt possessed at that point ... I had been seeing things then too as well ... I was just ... not myself ... not remembering you know little things I was forgetful ... my work colleague looked at me and she said to me "are you changing your medication" and I kept saying "no it's not the medication" ... it's not the medication" because I was so detero- so committed to having a family ... I have been ... biting off everybody's head and my mummy said "that's not right" ... I just wasn't myself.. the way that I explained to them and I have explained to my friends was "you know what? I feel like I felt possessed at that point" (Bethan PC)</i>
<b>Diana whilst changing from valproate to levetiracetam:</b>
<i>Me and my partner have been together a long time and I always loved affection from him ... but now he's like "what the hell's wrong with you?".. definitely mood swings.. I am very headstrong at the minute .. that was never me before and ... I'm starting to think what is it? (Diana PC)</i>
<b>Fiona changing from valproate to levetiracetam:</b>
<i>It was when the epilim was withdrawn that the side effects were really noticeable ... I had to come out of work.. ... I was quite tired and I was taking the two of them at the same and it was twice the drugs ... and then when the epilim was reduced it was terrible ... my moods were terrible and I would have been very irritable very tearful all of a sudden..just a nightmare!...so I had to come out of work ... I was off for 5 months ... because epilim obviously just knocked me out ... I then had a whole month of basically not sleeping at all and I was just awake round the clock and had to nearly teach myself how to sleep ... (Fiona AN)</i>
<b>REALISING MY CHILD (FROM PREVIOUS PREGNANCY) HAS BEEN HARMED</b>
<i>'he wasn't talking and people were saying "boys are slower than girls" and I thought it was his speech and then I had the Health Visitor out and then it all started from there but I got a big shock ... I thought he was just slow ... and it was good really early diagnosis and early intervention and got a statement put in place and I cried my eyes out ... autism ... but it was only the shock because I thought it was speech (Anna PC)</i>
<i>he's 16 months now and he's still not walking and he is quite slow .. he doesn't have much of an idea of balance and we ... -it's actually my mum that's a bit worried about him- he doesn't clap his hands ... he doesn't point just wee things like that I can't remember what they're called ... minor something or other ... wee development skills and I spoke to ..my own GP about it and ... he has actually referred him to the paediatricians because he says maybe he just needs a wee bit of encouragement to get him going but as yet I haven't heard anything back from them but when ... I spoke to Dr A [consultant neurologist] the last time when I was down there ... we just sort of asked him ... could it be linked with my epilepsy and the drugs that I was on ... but again well they don't really know but he was ... very interested to know it all and took a whole load of notes on it and that's really the only thing I have noticed ... he is a very content child and he would be happy just to sit and play on the floor with his toys and he gets up on all fours but he doesn't crawl and he ... just goes flat in his tummy and he rolls over but that's about it and he can obviously sit up but he's not ... attempting really to walk and I have been able to get him to stand maybe for a couple of seconds but now that he knows that you're doing it he's inclined to just fall forward ... so it's just one thing we are just worried about (Daphne AN)</i>
<b>LIVING THROUGH A STATE OF UNCERTAINTY</b>
<b>Taking a risk</b>
<i>So we'll take you off the epilim bit by bit and we'll get you on the vimpat [lacosimide] bit by bit ... and the vimpat isn't actually for my type of seizures (whispering) but ... it worked..I says "why not give it a go we've tried every tablet" (Anna PC)</i>
<i>I was excited ... I was ... you know "give me that" I was saying to ESN I would try it I was so excited ... trying for a family the future ... I'll give it a go ... the ESN ... made me aware "it doesn't work on all women but maybe it might work on you" ... she mentioned the research and it only works on ... very few women ... it was a population that was ... very few ... but ... the ESN said "the zonegran was the last tablet that I could use for a woman's epilepsy" ... and I was like "give me that and I'll try it" ... (Bethan PC)</i>
<i>it will be an interesting time now to see ... It's just hard like you just don't know the future or over the next couple of months like if you come off the tablets how it's going to affect or if you don't come off them you know and I suppose even the thought of getting pregnant ... like is that going to happen straight away or isn't it ... (Diana PC)</i>
<i>I suppose it is a worry all the time you're sort of thinking I wonder ... you know you just never really know how you're going to keep each time (Daphne AN)</i>
<i>I suppose ... it was just a leap of faith having to actually make that transition because it was quite hard at the time (Fiona AN)</i>
<b>Being hopeful</b>
<i>I thought he was jerking a wee bit when he was sleeping and I was concerned about that and ... we got him seen to ... but no he was fine ... it was probably just me being ... protective mother scared too probably because of me having epilepsy and didn't want him to have it ... but ... it could change later on we don't know yet ... if it changes it changes ... if he does get epilepsy ... we'll just have to deal with it! ... but at the minute he is a healthy boy just with autism (Anna PC)</i>
<i>... I'm not disappointed ... whenever I was about to finish my zonegran I was disappointed because I wanted to start a family but then I realised then whenever they all explained to me " ... think about it ... if you want to put yourself in that position ... what if something happens to you ... [your boyfriend] is gonna be left on his own with the wee one and then maybe touch wood" and then I realised yes ... my health comes first ... and then maybe have a wee baby ... my boyfriend says "I don't care about a baby ... we can wait until you are 100% and then we can see again" ... I thought that was the last of the tablets the zonegran ... and I remembered the ESN saying "no the Drs are still researching for more tablets that are working for other women" ... (Bethan PC)</i>
<i>I can't wait to see what happens over the next couple of months and hopefully touch wood I can get pregnant in the foreseeable future ... I suppose this is good to see that they are looking into ... this side of things ... it is definitely something that is appreciated by somebody like me who is sort of on your own and you don't know what to expect ... so it's good to see that something is being done ... and hopefully things will be a bit different ... in the future for other people (Diana PC)</i>

Table 2 (Continued)

## A TRAJECTORY OF BALANCE

## BALANCING MYSELF

... the consultant neurologist said that if something had gone wrong the first time he said there is another chance that something can go wrong again but.. so thankfully nothing did go wrong and hopefully nothing will go wrong this time but I suppose they are always looking out for things ... I suppose I did keep so well with my son ... you think hopefully I will keep well this time but it is always there...it's always something that you have there (Daphne AN)  
it's only now after that 20 week scan that I'm actually starting to allow myself to kind of try and relax into things a bit and try and be cautiously optimistic and hope that things work out ... because before I was scared to be hopeful of anything because I just didn't think it was going to work out (Fiona AN)

## RESTORING BALANCE

## Coming to terms with where I am now

You need to be healthy but you want another baby and I really do ... but now I'm lucky to have my son .. he is thriving and at nursery ... the special school ... it might only be for one year or two years but it could be until he's nineteen..but we just don't know.. whatever is best for my son (Anna PC)

I will take the right tablet for me if they can find it and if they can't my boyfriend says "don't worry about it ... it's not the end of the world" and my mum was saying and my friends were saying "you can always adopt you know" and I was all "I know we can adopt but just wait what the Dr and ESN what Dr C and ESN would say first" and in the future ... I'm not planning now ... I said "don't worry about it our time will come ... some things are meant to be ... let us go with the flow ... but I'm not going to do it with the epilim ... because now we both know I don't want to bring a child into our environment and maybe ..a disabled child could be bullied in school ... a deformed lip, back or whatever ... and we were like "we don't want our child going through that" (Bethan PC)

for years I just went on and never thought anything about my brain until now ... I always thought it was just work that was getting in my head and that's why I couldn't think as clear ... I just thought there was so much in my head ... I was going to bed at night and completely spaced out by the amount of stuff that was in my brain ... I was stuttering and stammering ... it's weird that a drug can do that to you (Diana PC)

I just sort of wondered was it linked ... you are on the drugs the whole time the full 9 months of pregnancy and you know if it doesn't have any effect whatsoever on the child you know it's very amazing ... If I was on a different drug and I was having fits all the time and didn't really know what effect it would have on the baby it would probably be harder (Daphne AN)

looking back now I think how on earth would I have ever managed a baby on epilim because I was so exhausted all of the time I don't even know how physically I could have managed it so it's probably looking back a blessing in disguise that those pregnancies didn't work out even though it was hard to sort of recognise that at the time but ... I hope that ... this is ... for the best ... I think (Fiona AN)

## Comfortable with change

I can now sit beside someone and do an interview which I wouldn't have been able to do without somebody with me ... the confidence ... it's growing and growing ... the consultant neurologist says to me now this was the happiest moment of my life ... he says to me 'you might never have another seizure in your life 99.9%' ... I'm happy...very happy the way it is. No I'm extremely happy (Anna PC)

After stopping zonisamide and going back onto valproate:

at the moment now that I am off it, it's not difficult ... because I have been getting better because I am back on my epilim chrono and clonazepam ... and I am still taking the folic acid every morning because the ESN knows that I want a family in the future and ... we're still at that process of my health comes first ... I don't mind the changing process because I know that my consultant neurologist and ESN want what's best for me too (Bethan PC)

I have decided to go down this path ... I will be just taking the keppra for now ... I'm finding myself fine at the minute' ... my mind was a lot clearer (Diana PC)  
like anything I suppose you just have to you have to just wait and see (Daphne AN)

## A new self

I was such a healthy person I'm back to getting this way again I'm going back to doing everything I want to do ... slowly but surely...and the wee man is number one ... ..and I'm getting myself number one ... I'm getting on with my life and ... starting to do things that I want to do ... ..now that I am getting the things that I have always wanted to do ... it takes time now it will take time if you were as controlled as I was it is going to take a lot of time but it's worth waiting on (Anna PC)

After deciding not to pursue parenthood whilst on valproate:

... I feel like focusing on marriage now can get our minds off a wee baby ... keep myself happy and healthy ... getting my health better ... focus on the present ..that's the wedding that's focusing on the present now coz for a long time I was thinking about the past when I was on zonegran and I was thinking about ... and over analysing what we do in the future with a baby ... what ifs what ifs but ... the wedding's something that we both can focus on now and just move on ... (Bethan PC)

that was never me before ... it just wasn't me ... definitely I have noticed a big change but hopefully it will go back to normal ... whenever you see the change.. like the way I see myself now is the way I seen myself before its mad how ... for years I just went on and never thought anything about my brain until now whenever I am realising ... my brain.. my god ... the clearness in my thought ... it's completely different now ... definitely clearer and not as confused (Diana PC)

[my husband] thinks I'm much better actually on this new drug because I was very tired on epilim but I suppose I didn't even nearly realise that at the time like if [the Consultant Neurologist] had said how are you ... I would have sometimes had sort of fuzzy heads or needed to go to bed or felt awful tired couldn't get up in the morning but ... that was just the reality of it...and I was so used to it coz I was on them for so long that was just me ... whereas now ... I'm up at the crack of dawn and [my husband] notices ... he thinks that I have more energy he thinks that it's better for me ... I look back now and think I was like a zombie for years..but at the same time there is the safety of knowing that you're on something that is controlling it and the fear of being on something that doesn't control it..(Fiona AN)

PC preconception participant, AN antenatal participant.

preconception period can be experienced as a "Shattering of Harmony". Recognising the extreme difficulties experienced whilst contemplating a change of medication, adjusting to the change, and adjusting to the possibility that change is not possible, could help deliver sensitive, appropriate and properly resourced person-centred preconception care which supports the woman throughout this period. However, currently in the UK, most women with epilepsy are not receiving effective preconception care [20].

Our sample of seven unselected women demonstrated evidence of inconsistent advice prior to conception, difficulty in finding the right referral pathway for preconception care, insufficient information about the potential mental and emotional effects of changing medication, insufficient proactive professional monitoring while changing medication, and care inequity, none of which suggest that a clear system of care is in operation at all times. However, those who experienced a specialist preconception clinic consultation were positive about its role in helping them prepare

for pregnancy, and there was also evidence of enormous resilience on the part of the women.

Current preconception recommendations for women on valproate direct clinicians to avoid valproate, provide information on the risks of valproate and ensure effective contraception for women on valproate [10]. However, this study highlights the difficulty in fulfilling these recommendations. Women may not be able to avoid valproate as there may have been allergy to alternative medications and valproate may be the most effective for their seizures. Provision of information about risks was dependent on being in a system of care for epilepsy but if women were seizure free on valproate they may have been discharged from specialist care. In the absence of preconception care, women relied on previous pregnancy experience to inform them, as previously found by Thompson et al. [12]. However, previous pregnancy experience may provide false reassurance about the impact of valproate. Previous absence of physical malformation may not indicate absence of neurodevelopmental delay, which

takes time to become apparent, and neither outcome is entirely predictive of the current pregnancy. In addition, women were exposed to inaccurate information from health care professionals who were inexperienced in epilepsy, also echoing previous literature [11].

An effective way of conveying evolving information on AEDs needs to be explored to facilitate accurate preconception information giving. Currently the MHRA guidance is weighed towards numerical risk communication. Option grids have been developed for shared decision making about valproate before pregnancy [21] and are argued as being beneficial when there are time constraints, but also include numerical information [22]. However, we found that women communicated their perception of risk in narrative rather than numerical terms, considering possibility (rather than numerical risk) of child disability, and impact on work and family. We hypothesise that women in this situation are not primarily using quantitative information in their decision making. Women did not express a need for more precise information about the exact magnitude of the risk, nor the exact nature of the potential disability. Our sample was relatively small, and this aspect needs further research in other populations. An individualised risk communication which is discussed with the woman and her significant others which is cognisant of the woman's own life circumstances may be most appropriate.

One of the most revelatory findings was the mental ill health and psychological changes which women experienced when changing medication. Anti-epileptic drugs have varying mood altering effects [23] and the changes described could have been due to withdrawal of valproate, the alternative medication given, or both. However, this is under-recognised in the literature on valproate or in preconception advice for women on valproate. Though our sample is small it represents the reality of changing medication – among seven women, one experienced a psychotic episode that meant she needed to go back on valproate, one found that she was more alert which had a positive impact on her lifestyle and another found that she was feeling more alert and as she used to be before valproate. Clinicians should be mindful of the ramifications of changing medication for the woman and her family when counselling women and in follow-up post counselling. Epilepsy Specialist Nurses are well placed to provide the support that women need [24] as they change medication, working collaboratively with the primary care team.

An overwhelming desire for motherhood was a driver for accessing preconception care and changing from valproate. Women who changed medication demonstrated a commitment and attachment to a future baby well in advance of pregnancy. 'Becoming a Mother' theory [25,26] recognises that mother identity including commitment and attachment occurs in pregnancy. Our findings add to their theory by identifying that mother identity may be attained before conception, and indeed that successfully accessing preconception care may depend on this. 'Maternalisation' is described in a qualitative study of 15 first time pregnant women interviewed in the first trimester [27] as a cognitive state limited to how the woman thought of herself, and how this was changing as she planned a pregnancy. In our study, maternalisation had a behavioural component, evidenced by information seeking behaviour, uptake of preconception care and medication changes to protect a future child. This adds to current understanding of role transition theory, and has implications for how women might be cared for in the preconception period. For example, if a change in medication has not been possible, there is a potential impact on self-perception, identity and emotional and mental health.

It was evident that the women in this study showed great resilience in the face of difficult choices and decisions such as withholding motherhood in the hope that a new drug with less

teratogenic risk might become available in the future. It is recognised that epilepsy impacts on women's reproductive decision-making [14,28] however, the decision to postpone pregnancy to avoid exposing a baby to valproate has not been previously addressed in the literature. There are examples of similar decision-making by women who are carriers of Huntington's Disease [29]. A decision to postpone pregnancy has physical implications for women in terms of ensuring effective contraception, emotional consequences as women come to terms with a future without children and re-establishing their own identity and social consequences as women reconfigure their relationship without children. This highlights the additional support required for women who remain on valproate following difficult decision-making and the value of efforts to find new medication options for women on valproate.

The fact that some pregnancies exposed to valproate continue to occur highlights the need for early follow-up of exposed children for early detection of problems and early intervention. The two women in our study who had previous children exposed to valproate described an absence of early neurodevelopmental input. The lack of a clear system of care both preconceptionally and postnatally could exacerbate socioeconomic inequalities, as receipt of care comes to depend on the mother's education and advocacy skills.

## 5. Conclusions

This study demonstrates that preconception care for women on valproate is experienced as a shattering of harmony within an overall trajectory of balance. The experience of women showed that healthcare improvements are needed, including regular review of women on valproate by Consultant Neurologists, fast track referral of women for preconception care, funding of Epilepsy Specialist Nurses to deliver care including monitoring of medication change and support for stress and the mental and emotional implications of changing from valproate, and early intervention for children exposed to valproate in pregnancy.

## Conflicts of interest

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## Appendix A. Questions for analysis of content, structure and purpose of clinical consultations

Pathway	
What is the referral pathway?	
What is the woman's purpose for attending?	
How long does it last?	
What is the format of the consultation?	
Consultation	
Health Care Professionals	What is the format of their contribution to the consultation?
Epilepsy Specialist Nurse	What does he/she communicate about? How does he/she communicate?
Consultant Neurologist	What does he/she communicate about?

(Continued)

Pathway	
Woman	How does he/she communicate? Does the woman know the HCP Health Care Practitioner? Who accompanies the woman? What questions did the woman ask? How did the woman respond to the information?
Accompanying person	What do they do? What do they want to know?
Follow-up on clinical consultation	What did the woman say about the clinical consultation in her first interview

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