

Re-working biographies: Women's narratives of pregnancy whilst living with epilepsy

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Abstract

This paper explores the multiple ways experiences of pregnancy and early motherhood come to 'rework' the biographies of women living with epilepsy. Pregnancy is explored as a temporarily concurrent status alongside the long-term condition of epilepsy. Narrative interviews were conducted with 32 women from across the UK. Analysis of these narratives suggests that biographical *disruption* and *continuity* are both useful in the conceptualisation of women's diverse experiences of pregnancy and epilepsy. Such findings challenge the notion that the presence of a condition over a long period of time leads to the normalisation of illness. Participants' narratives demonstrate that, for some, pregnancy and early motherhood may be disruptive and can raise concerns regarding an ever present condition that may previously have been taken for granted. Findings also indicate the need for a greater consideration of gender and care responsibilities, as well as explorations of concomitant conditions, in the theorising of biographies and chronic illness.

Keywords: United Kingdom; Gender; Biographical disruption & continuity; Pregnancy; Reproductive health; Epilepsy

[Bury's \(1982\)](#) seminal work on biographical disruption and chronic illness has been critiqued and developed in numerous ways, and demonstrates the enduring relevance of this concept within the field of sociology of health and illness ([Lawton, 2003](#); [Locock and Ziebland, 2015](#)). [Williams \(2000\)](#) argues that in order to develop this area further, an increased focus on the '*timing, context and circumstances* within which illnesses are "normalised" or "problematized," and the manner in which these identities are threatened or affirmed' is required (author's emphasis, 2000, p. 62). This article responds to Williams' call for researchers to be more attuned to issues of context in analyses of biographies through an exploration of epilepsy and pregnancy as (temporarily) concomitant states of being and the interplay between these conditions and women's identities. It expands the theorisation of biographies to consider a transitory state (i.e. pregnancy) alongside a long term condition (i.e. epilepsy), and by doing so challenges previous assumptions that conditions experienced from a young age or over a long period of time become normalised, and are in fact subject to periodic *reworking*. Such a challenge calls attention both to the need for better understandings of how concurrent conditions may shape the experiences and identities of those living with chronic illness(es) and a greater consideration of gender and care responsibilities within studies of biographies and chronic illness.

1 Literature review

In Bury's original formulation of biographical disruption, the concept elucidates the process by which chronic illness comes to threaten personal expectations, patterns and plans of everyday life. These disruptions may lead to a loss of confidence in the body and in social interaction causing a 'fundamental rethinking' of a person's biography and identity ([Bury, 1982](#), p.169). While biographical disruption became a well-established concept, the fundamental question remained regarding its utility 'to the diversity of experience which characterises chronic illness and disability in late 20th century Western society' ([Williams, 2000](#), p. 41). In response, researchers have elaborated upon the original theorisation of disrupted biographies, to include such configurations as 'biographical reinforcement' (e.g. [Carricaburu and Pierret, 1995](#); [Wilson, 2007](#)), 'continuity' (e.g. [Pound et al., 1998](#); [Sanders et al., 2002](#)) and 'oscillations' ([Bell et al., 2016](#)) to better capture a range of experiences and identity (re)formations in relation to illness or disability. These elaborations challenge the notion that chronic illness necessarily leads to a progressive deterioration of former self-identities. Instead chronic illness may come to be 'normalised' and/or an expected part of human experience. Work on biographical continuity shows how shifts to identity do not always occur after illness diagnosis (e.g. [Pound et al., 1998](#); [Sanders et al., 2002](#)). For example, older people living with arthritis articulated their condition as a normal part of the aging process ([Sanders et al., 2002](#)). Similarly, elderly participants described their experience of stroke as 'not that bad' and to be expected as one ages, challenging popular conceptions that strokes 'shatter lives' ([Pound et al., 1998](#)).

Normalising illness is not a phenomenon found solely amongst older adults, but also with children and young people. [Williams \(2000\)](#) argues that those who have lived with long-term illness or disability since birth or from a

young age may not experience as much disruption to their lives as those who receive a diagnosis as adults. When compared to dominant hegemonic notions of 'normality,' the lives of such younger individuals 'may appear (profoundly) disrupted. Yet, phenomenologically and existentially speaking, it remains the case that these biographies have not, in any real or significant sense, *shifted*. Continuity rather than change remains the guiding principle here ... ' (author's emphasis, Williams, 2000, p. 50). Studies with children and young people living with chronic illness support the argument that the management of the condition becomes quotidian (part of daily life), and thus their conditions are experienced as normal and not, or only temporarily, disruptive (e.g. Atkin and Ahmad, 2001; Admi and Shaham, 2007; Williams et al., 2009). However, one study with young people undergoing surgery for long-term conditions found a wide range of biographical experiences, with disruptions associated with their surgery, the ongoing management of their condition and the transition from adolescence to adulthood (Bray et al., 2014).

While considerations of biographical continuity have addressed issues of time and circumstance in the analysis of biographies, what remains neglected are considerations of individuals' experiences of concomitant conditions. There are notable exceptions, however, with research considering multiple conditions amongst older adults (e.g. Roberto and McCann, 2011; Clarke and Bennett, 2013). This article contributes to the growing body of literature on multiple conditions with an analysis of pregnancy as a temporarily concomitant state for women living with epilepsy. We argue that such considerations of concurrent conditions reveal more nuanced responses to illness and identity construction. An examination of the impact of pregnancy on the trajectories of women living with epilepsy brings to focus the need for a greater understanding of gender and caring roles in the theorisation of biographies and long term conditions. The continued absence of gender in sociological work on chronic illness in general (Bendelow and Williams, 1995; Thomas, 2003) and in theorisations of biographical disruption in particular (Ciambrone, 2001, p.50; Wilson, 2007, p.624; Clarke and Bennett, 2013) has been well noted. Exceptions include two explorations of the ways in which gendered norms and roles impact upon the experience of living with a long term illness (Fisher & O'Connor, 2012; Clarke and Bennett, 2013), and an early work on chronically ill women's management of pregnancy (Corbin, 1987), all of which demonstrate gender and care responsibilities as integral to the formation of self in relation to illness.

Biographical disruption has increasingly been extended beyond chronic illness and disability to include a wider range of conditions (Locock and Ziebland, 2015). Reproductive health has been one area where these new applications of a classic concept have been fruitful (Locock et al., 2008; Sevon, 2012). For example, while women's experiences of nausea and vomiting in pregnancy (NVP) may be seen as normal part of pregnancy by women themselves and health professionals, NVP can be highly disruptive in day-to-day life, parenting and social functioning (Locock et al., 2008). And biographical disruption and continuity have been found to be concepts that resonate with women's narratives of transitions to motherhood (Sevon, 2012). Thus pregnancy itself, like chronic illness, impacts upon biographies, echoing sociological understandings of how women's self-identities come to be refracted by transitions to motherhood (Bailey, 1999).

In our conceptual framing of epilepsy and pregnancy as (temporarily) concurrent conditions, we refrain from employing the word 'condition,' with its negative connotations of ill health, in relation to pregnancy. There is a lack of suitable language when considering epilepsy (as a condition of ill health) alongside pregnancy (as simply a neutral condition of health). Given the social history of the pathologized pregnant body (Martin, 1989), it is imperative to stress that pregnancy is not considered here as a state of poor health, but of altered health. Thus, in lieu of the term 'condition' we employ the terms 'state' or 'status' of health in reference to pregnancy.

Pregnant women undertake emotional and embodied labour when looking after their own health and that of and their unborn babies (Gatrell, 2011). Thus pregnancy, like mothering and caring for infants, is a form of gendered, informal 'carework' (ibid.). Pregnant women living with epilepsy not only perform the carework required of 'good mothers,' but also maintain the 'learned moral work' of being 'good patients' as they continue to manage their condition (Thompson et al., 2008: p.60). This article seeks to contribute to more nuanced explorations of the effects of illness on gendered self-making through considerations of how the carework of pregnancy and early mothering come to intersect with the (moral) work of managing epilepsy.

2 Methodology

This paper draws on qualitative research undertaken as part of the EMPIRE (Anti-Epileptic drug Monitoring in PREgnancy) randomised controlled trial (RCT). EMPIRE is a multi-centred UK-based RCT comparing proactive and reactive strategies for anti-epileptic drug (AED) regimes during pregnancy (see trial website for more details: <http://www.blizard.qmul.ac.uk/research-project/1401-empire.html>). Alongside this trial, the authors Annalise Weckesser (AW) and Elaine Denny (ED) conducted narrative interviews exploring women's lived experiences of pregnancy and epilepsy. Ethical approval was obtained from the West Midlands-Coventry and Warwickshire National Ethics Research Service (reference code 11/WM/0164) and Research and Development approval was received from all NHS Trusts involved. Participants were initially approached by research nurses and midwives to take part in the RCT and/or qualitative study. After informed consent was obtained, AW contacted women to arrange interviews at a location and time convenient to them. Women were interviewed twice; once upon recruitment to the study, and once again approximately six weeks after giving birth. The first antenatal interview was conducted in March 2012 and the final postnatal interview was conducted in January 2014. Antenatal interviews lasted between 1 h to one and half hours, and follow-up postnatal interviews were a half hour to an hour. Antenatal interviews sought to capture participants' narratives of pregnancy and epilepsy, while shorter follow-up interviews focused on women's reflections on their pregnancy and epilepsy management, as well as their experiences of giving birth and early motherhood.

The majority of antenatal interviews were conducted in women's own homes (n = 18). However, some participants preferred to be interviewed during their antenatal hospital appointments (n = 7), by telephone (n = 5), or in cafes (n = 2). In common with Novick (2008) we found participants to be at ease over the telephone and open to disclosing intimate information. Before interviewing, AW and ED re-iterated consent with women by obtaining verbal

permission to record interviews. Participants were recruited until saturation was reached (Bowen, 2008); saturation was determined jointly by AW and ED when no new themes or relevant information emerged from ongoing analysis of interview data. Following initial interviews, women were given £20 gift vouchers as appreciation for their time and participation. Theoretical sampling (Glaser and Strauss, 1967) was employed to purposely include women from different geographical regions, with a diversity of socio-cultural backgrounds, varied histories with epilepsy and a range of neurological symptoms. Thirty-two women participated in interviews, of whom 21 had enrolled in the RCT; eleven women agreed only to take part in the qualitative study. This paper is based on 32 antenatal interviews and 24 follow-up postnatal interviews. Eight women did not participate in second interviews: one returned to her country of origin, two withdrew from the RCT, and five were unable to be contacted. Participants came from both urban and more rural areas, including London (n = 11), Birmingham (n = 8), Blackburn (n = 3), Cardiff (n = 2) Shrewsbury (n = 2), Sheffield (n = 2), Liverpool (n = 1), Stafford (n = 1), Gwent (n = 1) and Worcestershire (n = 1).

At the first interview, over half were becoming mothers for the first-time (n = 18) the remainder having at least one child. Women ranged in age from 19 to 42 years. The mean age was 31 years. More than half of participants were married (n = 18) the rest living with partners (n = 10), living separate from partners (n = 2) or single (n = 2). Women worked in professional occupations (n = 17) and in retail (n = 2) or were unemployed and/or full-time mothers (n = 12); one was a full-time student. The majority of participants were born in the UK and self-identified as White British (n = 21), others identified as British Asian (n = 4) and British-Black Caribbean (n = 1). A number of participants had immigrated to the UK, including three who identified as White European, and one each as Chinese, Black African, and White American.

Participants had varied histories with epilepsy, with one only being diagnosed within the past year, and at the other end of the spectrum, a participant had lived with the condition for 29 years. On average, women had lived with their condition for 11 years. Women also experienced a wide range of neurological symptoms. Participants self-identified their seizure types, from tonic clonic seizures (which constitute more popular images of epileptic convulsive seizures, with a person losing consciousness, their muscles stiffening and jerking), to myoclonic seizures (involving the brief, shock-like jerking of muscles) to absence seizures (absences in awareness, which women often described as like 'déjà vu' or an 'aura'). Some women experienced more than one type of seizure at different stages in their lives, and the frequency of seizures also ranged among women and over an individual's life. The majority of participants controlled their seizures by taking AED medications including Lamotrigine, Keppra, and/or Tegretol. One participant reported self-management through lifestyle adjustments (avoiding alcohol, getting regular sleep, etc.) and another had only been recently diagnosed with epilepsy and was not yet on medication.

We conducted a review of qualitative literature on the experiences of pregnancy and reproductive health whilst living with pregnancy (Weckesser and Denny, 2013) which informed the semi-structured topic guide. In-depth, narrative interviews were conducted using open-ended questions that sought to elicit participants': past histories and experiences with epilepsy; their present, everyday management of the condition during pregnancy and after giving birth; and their future hopes for themselves and their babies in terms of emotional, social and physical health and wellbeing. A narrative analysis was adopted as this method has much to contribute to studies of chronic illness and biography. As Riessman notes, '[t]elling narratives is a major way that individuals make sense of disruptive events in their lives' (1990, p.1199) and it is through telling one's story that 'we create our realities and ourselves' (ibid.). Within this narrative mode of analysis, a thematic approach was undertaken; a method that allowed for the identification of common themes across cases whilst enabling individual women's stories to remain intact (Riessman, 2008). Antenatal and postnatal interviews were analysed together as one data set. AW coded data with the qualitative software programme, QSR Nvivo, undertaking analysis through constant comparison technique. ED and a member of the trial team checked this analysis by independently coding a portion of interview data. These analyses were brought together to identify common and overlooked themes as well as deviant cases.

3 Findings: women's re-worked biographies

Findings are presented here as short case studies of women's stories in attempts to keep women's narrative accounts intact. These cases are supported with further evidence from additional participants to illustrate both cross-case commonalities and diversities of experience. Results are presented in two sections, the first provides cases of women's experiences of biographical disruption, and second cases of biographical continuity. Quotes from antenatal interviews are indicated with the initials 'AI' and postnatal interviews with 'PI.'

Our analysis did not show any shared characteristics, such as time lived with epilepsy nor severity of seizures, amongst participants reporting experiences of disruption or continuity. One participant was still experiencing the initial disruption of her diagnosis, which she had received within the past year. Her case differed from the majority of participants who had lived longer with, and who had normalised, their epilepsy prior to pregnancy.

3.1 Section 1: cases of disruption in pregnancy, seizure & early parenthood

The following section provides three cases to illustrate disruptions that some women experienced at different stages over the course of their pregnancies. Each case provides an example of an event during which the biographies of participants, which would previously be characterised as continuous, came to be interrupted. These time points include becoming pregnant, a seizure during pregnancy, and early postnatal parenting experiences.

3.1.1 Disruption at pre-conception & becoming pregnant

Riva (all participants have been given pseudonyms) has lived with and managed her epilepsy for nearly twenty years. When reflecting upon how her epilepsy affects her day-to-day life she stated:

... I think I was very, very lucky because my epilepsy has generally actually been very well managed. So the [AEDs], even though at different phases of my life, at one point I tried to come off it and obviously I had a seizure and I had to come back on, but I haven't had like that many seizures in my whole life. So it was, it was very well managed, so I think before I started getting pregnant, you just mentally assume you're pretty much normal ... (AI)

Riva, like many other respondents, described herself as 'lucky' because her epilepsy is 'well managed' meaning that her seizures are relatively controlled and occur infrequently. She commented, 'I could get up every day, I would have my medication, erm, I could go to work and have a normal life and go back home and, you know, it wasn't something that would impact me greatly.' Her seizures were so few that prior to her pregnancy she stated that she felt 'normal.' This biographical continuity and feeling of 'normalcy' is characterised by her condition being managed to the point of feeling that it had little effect on her life over the past twenty years. However, she found pregnancy disrupted this feeling of normality. She continued:

... I think it doesn't really dawn on you until you actually start thinking about having a family that actually [epilepsy] does have an impact, like much more of an impact than you originally thought of it as really ... So before we started having, or thinking about having a family, um, the one thing that had always been made clear to me since I'd had my epilepsy is that if I ever wanted to have children ... I need to go and see the doctor, um, because my medicine ... I mean it wasn't really that clear how, er, detrimental the medicine was [to the fetus] ...

So for example, yes, when I first started work, you know, or they ask you "Do you have a disability?" and I always tick like "No, of course I don't have a disability I'm fine." Like, you know, I can live a perfectly normal life. But I think the whole process of getting pregnant and now being pregnant has kind of made me realise that actually that's not really quite the case as I initially thought ...

... I've never felt like I was embarrassed or ashamed but I just never felt the need to tell anyone. So, you know, my family knew and my boyfriend, or my current husband, he knew, um, but to be honest, er, I didn't really tell anyone else ... And actually it wasn't sort of until I was in the process of trying to get pregnant that actually I thought "you know what I need to tell my boss," yes my boss needs to know, if something happens to me in the office ... (AI)

Riva's experience is representative of the majority of participants (n = 22) who reported having well managed epilepsy, with few, if any, experiences of symptoms (including seizures, shakes or auras) for a long period of time prior to pregnancy. For these women, their condition was not something they thought about on a day-to-day basis beyond 'taking a tablet' which allowed them to 'get on with it' and live their lives 'as normal.' However, at the point of preconception and/or learning one is pregnant this 'normality' may be disrupted due to the possible teratogenic (interference with foetal development) effects of AED medication. As Riva stated above, epilepsy 'does have an impact' on one's life (and one's child life) and thus may be (temporarily) disruptive where the condition had previously been taken for granted. Riva's identity in relation to disability also came to be reconsidered. Whereas previously she would not identify as 'disabled' because despite her epilepsy she was 'fine' and able to live a 'perfectly normal life', becoming pregnant complicated this previous sense of self as she felt she must disclose her epilepsy to her employer. Riva now considered epilepsy as a concern that could impact upon her work and wellbeing.

Some women (n = 7) who had not previously informed employers regarding their epilepsy stated that their pregnancy created a new need for disclosure. Like these participants Riva reported that she had not previously informed her employers about her condition because she had not felt it relevant as it had not impacted on her ability to carry out her work. While Riva's immediate family and partner, as well as close friends, knew about her condition, she now chose to inform her employer in case 'something happened at work,' in particular, a seizure. Similarly, participants who first told their employers about their epilepsy when becoming pregnant did so because their condition could now impact upon work performance. Reasons for disclosure included: being at increased risk for seizure during pregnancy (and wanting colleagues to know how to react during and after a seizure if the need arose); missing work due to being designated a 'high-risk' pregnancy, which required more frequent antenatal clinic visits than if they had non-'high risk' pregnancies; and requiring changes to work loads and/or patterns to allow women more rest, especially in the final trimester, in order to prevent seizure. Women with pregnancies unencumbered by long term conditions often have to ask for similar accommodations from employers. However, for those women living with epilepsy, pregnancy is a concurrent, temporary status that requires additional considerations and brings their condition to the forefront of their minds when it had previously been something that had not impacted upon their day to day life.

3.1.2 Disruption from pregnancy-induced seizure

As stated above, women are at heightened risk for seizure during their pregnancies (Adab and Chadwick, 2006), which is due to increased blood volume and consequent decrease in blood concentration levels of medication as the pregnancy progresses and weight is gained. Seizures at this time can be highly disruptive to women's day-to-day lives. Sandra experienced a seizure during her first pregnancy, and found the experience so disruptive that she considered not having a second child. She was diagnosed eighteen years ago, prior to her first pregnancy, and considered her epilepsy well managed. Sandra talked about the experience of having a seizure in her first pregnancy:

My last pregnancy I got to 20 weeks and I had a nap in the day, and I woke up and I fitted, I was in shock because I hadn't had a fit and I'd been so good taking my medication and the same thing happened the next morning and I woke up and then I had a fit ... I thought maybe I had forgotten to take my medication. And when everything's on your driving licence you don't want to risk it. But then I knew I'd taken my medication that night and when I had the fit the next morning I knew I can't keep something like that [to myself], I have to do something ... (AI)

Sandra's epilepsy midwife increased her medication dosage and the seizures ceased, however, she lost her driving license for a year. She lives in a rural area where driving is essential and this impacted upon her ability to travel with her baby which led to feelings of isolation. Following maternity leave, being unable to drive complicated her return to work as she had to navigate poor public transport. Sandra stated that it was the most 'depressing time without a driving licence. I didn't really know how much it meant to me ... And it put me off getting pregnant again, because the thought of losing my driving licence again, it was too much of a risk.' Due to this experience, for her second pregnancy Sandra decided she would proactively and pre-

emptively increase her medication to prevent a seizure whether the epilepsy nurse supported the decision or not.

Further influencing Sandra's desire to take control of her medication during this pregnancy was the death of an acquaintance, who also had epilepsy, from SUDEP (sudden unexpected death in epilepsy). Sandra stated, 'I went a bit psycho, believing I was going to die of an epileptic fit and stuff and I ended up doing so much research on sudden, well, death with epilepsy. So yeah, it was scary.' She experienced severe insomnia and feared passing away in her sleep, just as her friend had, and worried about not being there for her husband and children.

Sandra may represent an outlier case as no other women with well controlled seizures previous to their pregnancy reported having a seizure during pregnancy. Further, no other women expressed fears of SUDEP, despite this being the main cause of epilepsy-related death during or shortly after pregnancy amongst women in the UK (Edey et al., 2014). This may be due to Sandra's personal experience with this fatal complication through the loss of her friend. Additionally she is a health care provider and thus may have more access to information regarding the risk of SUDEP during pregnancy.

While Sandra's experiences may not have been shared by other women participating in this study, the possibility of an unexpected (and potentially fatal) seizure was one that, for many, had to now be considered once becoming pregnant. The seizure brought on by Sandra's first pregnancy was highly disruptive, impacting acutely (albeit temporarily) upon her movement through the loss of her driving licence. This disruption shaped her ability to work and maintain social connections with friends and family, influencing her decision whether to have more children, and intensifying her fears of SUDEP, which in turn she felt impacted upon her psychological wellbeing. These experiences align with Bury's (1982) conceptualisation of disruption and how chronic illness comes to threaten one's everyday life. Thus, pregnancy-induced seizures present another possible time point at which the day-to-day lives of women may be interrupted where their condition had, prior to that event, come to be normalised.

Participants described how they weigh-up the risk and benefits around taking their AEDS with considerations of their health, the health of their baby and the context of their lives. Some women felt that it was particularly important to keep taking, or (like Sandra) to increase, their AEDs during pregnancy to minimise the risk of seizures. Others chose to stop or reduce their medication for the first trimester due to the perceived risk of malformations to the fetus. Many in this latter group resumed or increased their medication in the final trimester when risk of seizure was seen as higher. The rationale underlying women's management of medication was guided by a feeling of maternal responsibility towards their unborn child as well practical concerns of needing to remain seizure-free in order to better care for their baby.

3.1.3 Disruption in early mothering

For many women, especially those for whom lack of sleep is a seizure trigger, the sleep deprivation that comes with a newborn, which is viewed as part and parcel of early motherhood, can be particularly challenging. This was the case for Fiona who had a prolonged, week-long labour during which she had little sleep, and who then describes further sleep deprivation during her first few weeks after returning home from hospital with her baby:

It was really incredibly hard. And all of this like, you sleep when the baby sleeps, it's like, okay, but I might need to eat when the baby sleeps. I might need to go to the loo when the baby sleeps ... I know there are some women who cope with it, but that was the worst thing for me, the sleep, by a million miles. (PI)

When Fiona finally felt she 'could not have gone another week without sleep,' and was concerned she could have a seizure when she had been seizure-free for 5 years, she and her husband hired a night nanny. On making the decision, she says she thought

I can't leave [the baby] with somebody else and oh, I can't do that, and overnight, and that's so bad and ... you know.

[Interviewer: Why did you think it was bad?]

Just because you feel like you shouldn't ... you should be able to do it ... [I]t was fine leaving her with my husband, but I found it quite hard just leaving her with other people ... And, you know, I don't know anyone else who has had a night nanny, apart from my sister, so you're kind of like, oh God ... I felt like I should be fine with this, I should be able to do it ... (PI)

Fiona knew she was fortunate in that, unlike most new mothers in this study, she could afford a night nurse. However, she reported feelings of guilt due to her inability to perform care duties that she believed, as a mother, she 'should be able to do' and that most women must manage alone. Here, her epilepsy and the potential seizures brought on by sleep deprivation disrupted her notion of what she 'should' be able to do as a mother.

A number of women (n = 6) expressed similar sentiments of not being able to mother 'properly' because they needed family members to do overnight feedings and night care of their babies. One woman moved into the home of her mother-in-law, feeling guilty that her mother-in-law had taken on many of the care duties of her baby. Another participant also expressed feelings of guilt because her husband had to do 'double duty,' working during the day and then feeding their newborn through the night. Meanwhile she slept in her own room so she could get the uninterrupted night's sleep she required in order to stay well. While sleep deprivation may be a problematic 'badge of honour' new mothers feel pressured to display, these women felt they could not take part and thus their new care responsibilities were at odds with/disrupted by their long term condition. Participants' engagements of support with infant care at night (from a partner, mother-in-law and night nurse) were responses to disruption involving the 'mobilisation of resources' (Bury, 1982: p.176). One participant's financial means to hire assistance, with others relying on familial networks, reflects how socio-economic circumstances shape access to resources for mitigating

impediments associated with chronic illness (Bury, 1982: p.177) and/or pregnancy and the transition to motherhood.

3.2 Section 2: cases of continuity: 'It's twaddle really'

While at different points throughout some women's pregnancies disruptions were experienced through their need to think about, and now accommodate, a previously taken for granted condition, for others, such changes were experienced as less of a shift. Jenny had her first seizure at the age of 17 and after trying multiple medications to control them, she found an effective medication and dosage which she combined with self-management through regular sleep. She had been pregnant once before but had a late miscarriage. Her epilepsy diagnosis also led to her losing a job working in a factory. Despite these hardships, she did not articulate her epilepsy and current pregnancy as disruptive factors in her life.

But like see people, people say oh [epilepsy is] a disability, I don't claim it as one ... It don't affect me in anyway so I don't see why it should be a disability to me ... I just don't think if a woman has got epilepsy [that she] should be scared to have a baby because she could be like me, everything is fine, no worries at all. So I wouldn't even worry about thinking, "Oh I can't have a baby because I've got epilepsy," because it's twaddle really. (AI)

Jenny's current pregnancy was going well despite her initial worries that she could miscarry again. She was concerned that she could have a seizure during pregnancy, but was reassured that her medication would prevent this. Despite these experiences of hardships, she still articulated her experience of pregnancy while managing her epilepsy as 'fine' with 'no worries at all.' Note that Jenny's gendered narrative of coping may be one that she presents in the context of an interview. As found by Werner et al. (2004), women living with chronic conditions may present 'moral plots' during narrative interviews, in which their own (positive) strength overcomes what is seen as (negative) illness talk (i.e. complaining).

Another participant, Seren, experienced her first partial seizure (a seizure that occurs in just one area of the brain) two years previously, after she had already had two children. Although in this pregnancy she worried about the effects of her AED medication on the fetus, in comparison to family members who experience what she considered to be 'real' epilepsy (that is recurrent tonic clonic seizures) she saw herself as having 'mild' epilepsy and thus worried less. In regards to her feelings about being pregnant while managing her epilepsy, she stated that she felt, 'Fine, because I've not had any [seizures] ... I haven't had any change in my seizures or anything, I feel it doesn't affect me. I don't really think about it. It's not a problem.' And her thoughts regarding this pregnancy, 'Just normal things really, you know, sort of like what [the baby will] be like, and ... We don't talk about ... we don't worry about that they might have my epilepsy or anything, just the normal what he'll look like, and you know.'

Seren, like Jenny, saw her pregnancy as straight-forward as she was able to think about 'normal things.' Her experience of epilepsy during her pregnancy was continuous with her pre-pregnancy experience. She felt that it was a more 'mild' and controlled condition than those of her siblings and thus one she said that does not affect her and 'is not a problem' in her everyday life.

3.2.1 Continuity in early motherhood

Women and men living with epilepsy are advised to modify how they carry out some of their care duties to safeguard children from being harmed if the parent has a seizure. These modifications include things such as not bathing their baby alone, changing nappies and breastfeeding while sitting on the floor, and refraining from co-sleeping. Half of women interviewed postnatally reported making one or more of these adjustments (n = 16), but did not necessarily experience these as disruptive to their ability to care for their newborns.

Simone responded to whether she has had to modify how she cares for her baby because of her condition:

I do think, I don't do any co-sleeping ..., and my partner does the bathing every night really, not because I don't want to, I mean that's the only time he gets to spend with [our baby] really because he's at work all day so it's quite good for him.

Yeah, I do think about ... I don't know if I think so much that I'm going to have a seizure, to be honest, because I think if I'd have had a seizure it would have happened a lot earlier so maybe I don't think about it as much. I thought about it a lot the first week, maybe two weeks, and now not anymore, not anymore. But I don't bathe him when I'm alone.

Maybe I wouldn't have done [co-sleeping] anyway, I'm not sure, I probably would have read more into it, I've just decided not to do it, but I probably would have read more about it. (PI)

Other women said they did make some modifications, but like Simone did not experience such changes as disruptive, instead reporting that they became 'habits' and part of the care routine. Further, it may be a challenge, as it was for Simone, to disentangle what care choices one makes to accommodate epilepsy and what one would do regardless of the condition.

4 Discussion

Bury, in a 2013 conversation with Locock and Ziebland (2015), stated that it would perhaps be more productive for sociologists to view biographical disruption as a heuristic device rather than a concept. This would imply an

exploratory tool rather than a fixed theoretical abstraction representing the experiences of *all* those living with chronic conditions. This article has employed biographies in this manner; using them to think through women's experiences of pregnancy and early motherhood whilst managing their epilepsy. Doing so reveals that women undertake a re-working of their identities during this transitional time in their lives.

As this study was carried out alongside the EMPIRE trial, including only women who chose to have children, there is a risk of bias as these women may have more well-managed seizures and fewer side-effects associated with medication. Further work with women experiencing more severe or less controlled seizures would be beneficial, exploring how this may differently shape the making of identity and the making of family. Participants not living with a partner (n = 4) were among those not available for second interviews. Their experiences of issues such as sleep deprivation may be very different from those who have a cohabitating partner. Future research would also benefit from a more ethnically diverse participant sample. Despite these limitations, this study's strength lies in the original contribution it makes to furthering understandings of women's experiences of epilepsy, pregnancy and reproductive health, where previously there was a dearth of quality, in-depth qualitative research (Weckesser and Denny, 2013). To our knowledge, this constitutes one of only two studies to directly examine women's experiences of pregnancy whilst managing epilepsy, the first being that of Thompson et al. (2008).

The pregnancies of women diagnosed with epilepsy are often automatically labelled 'high-risk.' It is beyond the scope of this paper to fully unpack both the concept of risk and the ways in which a single diagnostic category of epilepsy may fail to capture the wide spectrum of seizures, symptoms and relative risk experienced by women. Two women in the study were advised against having children due to the risk to themselves and their baby, indicative of how women still receive conflicting information from doctors regarding whether they should start a family. Participants, largely accepted the high-risk label for strategic reasons, viewing it as a means to better access to antenatal services, which offered a sense of security.

Like Thompson et al. (2008) we found many participants experienced tensions when attempting to undertake the carework of being a 'good mother' (for example, by protecting the foetus from potential teratogenic effects of AEDs and/or staying up overnight with new-borns), while also continuing to be a 'good patient' (for example, compliance with medication and/or getting regular sleep). Such conflicts were evident in the case of Fiona, who experienced feelings of maternal guilt when – in order to prevent seizures – she could not stay up through the night with her baby, which she felt 'as a mother' she 'should be able to do.' Many women without chronic illness also experience 'turbulent transformations' and biographical disruption during the transition to first-time motherhood when they perceive themselves unable to live up to dominant narratives of 'intensive mothering' (Sevon, 2012). For pregnant women living with epilepsy, negotiating being a 'good mother' while also remaining a 'good patient' entailed a reworking of identity. This tension was further compounded for those participants whose epilepsy had come to be taken for granted prior to pregnancy.

This ongoing reworking of identity during pregnancy and early motherhood for women living with epilepsy resonates with the findings of Trusson et al. (2016), that for women with early stage breast cancer, the post-diagnosis and post-treatment 'new normal' is not a static 'achievable state,' but instead 'a continual process of renegotiation of identities, daily lives and futures as time passes and lives evolve (Trusson et al., 2016: p. 128). Bell et al. (2016) offer up a similar reconceptualization through their analysis of the narratives of people with Meniere's disease and those of their family members, which focused on transitions of parenthood, caregiving and retirement. Rather than conceptualising the onset and progression of chronic illness as linear, they argue it is better theorised as 'one of many "biographical oscillations" encountered in the life course that reroute us between continually shifting, often "messy" and unanticipated life trajectories (Bell et al., 2016: p. 183). Although pregnancy was not an unanticipated new status for women in this study, moving between non-pregnant and pregnant states and transitioning into motherhood and new care roles may also be conceptualised as 'oscillations' with ongoing reworkings of identity, rather than as a form of linear progression through a temporary disruption.

This article contributes to more nuanced explorations of the effects of illness on gendered self-making through considerations of pregnancy, early mothering and caring responsibilities as key identities through which the experiences of illness come to be refracted. Wilson (2007, p. 624) argues that previous conceptualisations of biographies and illness have taken an individualist approach, focusing on how a chronic condition comes to prompt a 'fundamental rethinking of the [individual] person's biography and self-concept.' In the narratives of women in later life, who are managing multiple chronic illnesses, Clarke and Bennett (2013) found that their accounts often focused on how their conditions affected their significant others. Such accounts reflect the gendered norms to be nurturing, selfless, and sensitive to the needs of others. The narratives presented here of women living with epilepsy are similarly gendered, with women emphasising not just how their condition impacted upon themselves as individuals, but upon their day-to-day roles as mothers and their ability to care for their babies. A focus on reproductive health and motherhood revealed less individualistic and more contextualised biographies.

5 Conclusion

This study contributes to the current body of knowledge on biographies and chronic illness through a response to Williams' (2000) call for a greater focus on circumstance and context in biographical analyses. It does so by exploring the various ways in which the biographies of women living with epilepsy come to be 'reworked' at the time of pregnancy, early motherhood, and the ongoing management of their condition. A narrative analysis found that both biographical disruption and continuity feature in women's diverse experiences of pregnancy and epilepsy. While for some women, pregnancy and early motherhood were points in their lives at which epilepsy, which may have previously been taken for granted and normalised, came to be problematized; for others, such changes were experienced as less of a shift.

The exploration of pregnancy as a concurrent, temporary altered health status alongside the long term condition of epilepsy challenges the assumption that the presence of a condition over a long period of time leads to the normalisation of illness even during periods of changed circumstances. The examination of the role of gender and care responsibilities in the interplay between identity (re)formation and illness revealed examples of less individualist biographies; identities that were formed not just on the basis of impact of illness on the self, but also the impact on others. Thus, both the consideration of concomitant conditions, as well as the role of gender and care responsibilities, opens up and expands understandings of the diversity of biographies.

Uncited references

Bury, 2001.

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Highlights

- Pregnancy, early motherhood 'rework' the biographies of women living with epilepsy.
- Biographical *disruption* & *continuity* found in narratives of pregnancy & epilepsy.
- Pregnancy can be disruptive for those living with 'normalised' chronic illness.
- Need for consideration of gender, carework in biographies & chronic illness studies.

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