Reflection on a pregnancy complicated by obstetric cholestasis

Gemma Steele shares her personal reflection on her first pregnancy which was complicated by obstetric cholestasis

SUMMARY Gemma Steele, a midwife, shares her personal reflection on her first pregnancy which was complicated by obstetric cholestasis. Gemma gives insight as to how debilitating it can be suffering from this condition and highlights that a woman can be diagnosed as early as six–eight weeks gestation. For this reflection, Gemma used Gibbs' reflective cycle (Gibbs 1988) to help explore the experience and guide the reflective process (Bulman 2008).

Keywords Obstetric cholestasis, intrahepatic cholestasis of pregnancy, stillbirth, itching, pruritus, liver, midwife

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As a midwife I knew about obstetric cholestasis (OC), but I did not appreciate how early it can occur and how devastating living with this condition can be. When I became pregnant with my first child I was excited, but with the medical knowledge that I had about what can go wrong I did approach it with trepidation in case the worst should happen.

The onset

The early weeks were perfect; I wasn't even nauseous. But at 11 weeks I developed slight itching. I thought nothing of it and assumed it was just due to hormonal changes. However, the itch slowly worsened over the coming weeks. It was not isolated to any part of my body, and by 14 weeks it was affecting my sleep and also which clothes I could wear.

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I discussed this with both midwives and doctors at my place of work and they all had the same response: *'It's too early for OC, it must be hormonal'*. I was not convinced that this was normal, so I had a liver function test (LFT), the results of which were slightly elevated. Again no one seemed concerned and I was prescribed topical ointment for dry skin which, I was told, would stop the itching. I had started to take anti allergy tablets and I also tried all the topical creams available; but nothing relieved the itch.

The plan was to have another blood test at my next appointment (16 weeks). I did some research and found that women can be diagnosed with OC as early as six-eight weeks gestation. Knowing this I was then praying that it wasn't OC because of the risks to the baby. On the other hand if it was, I would have an explanation and could start treatment.

Depression

At 16 weeks I was feeling extremely ill. I had no appetite, dark urine and pale stools; the itching had increased in intensity; and I was not sleeping. On reflection I realise that I was severely depressed (I remember whilst driving my car, thinking that everything would

PERMISSION OF GEMMA STEELE

stop if I just drove into a tree at 100 miles per hour). The itching was so intense that I was covered in scratches from my attempts to relieve it. I found that trying not to scratch the itch was impossible – the more I tried to ignore it, the more painful it became. When my feet were having a particularly bad phase I would rub them together; the itching was so bad that I actually rubbed off a circle of skin larger than a 50 pence piece.

I found I avoided going out other than to go to work, so that I didn't have to wear any clothes. I used to wake up, have a bath and then put on a clean pair of pyjamas, but I only had two pairs that I could cope with.

Diagnosis

All day I would worry, dreading the night because the itch was even more intense then. I was exhausted from lack of sleep, so I tried everything to make the nights easier, even sleeping with two fans pointing at me (because the slightest feeling of warmth would send me into an itching frenzy).

When my blood tests were repeated at 16 weeks my ALT level was 210 IU/L, but still the doctors at my place of work were sure that it must be something else as it was 'too early' for OC. I was screened for hepatitis, but I also insisted that bile acid tests were done.

The hepatitis screening came back negative, but the bile acids came back at over 205 µmol/L. My consultant then agreed that it must be OC, but she admitted that she had not seen anyone diagnosed so early. I saw a hepatologist and was started on ursodeoxycholic acid (UDCA) (1500 mg a day), with a plan to perform another blood test in two weeks.

Once I had the initial blood results and the diagnosis of OC I convinced myself that I would suffer the loss of my baby. I just couldn't see how he could survive when my body was poisoning him with such high levels of bile acids. I felt a failure. I had been dreaming of being pregnant and enjoying my pregnancy, but instead I felt extremely ill and that I couldn't even keep my baby safe.

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Finding support

Once I had started UDCA the ALTs slowly normalised and the bile acids started to reduce. I found help with OC Support and read about other people's experiences. Their forum gave me a place to vent my frustrations, about having this condition, with people who understood what I was going through.

I looked at my hospital's policy on OC (which was more relevant for when a woman was diagnosed in the third trimester) and arranged weekly blood tests to be performed at the day assessment unit. I continued working as long as I could. I had my anomaly scan, which was normal, and my bloods carried on slowly improving.

By 20 weeks gestation my depression had considerably improved, but the pruritus had not calmed at all. My blood results were too slow to improve, my bile acids still remained over 100 µmol/L, so the UDCA was increased to 2g per day. By 24 weeks I could no longer function at work and had to go on sick leave. At 25 weeks my bile acids started increasing again and were now over 180 µmol/L, and because the levels had never been under 60 µmol/L my obstetric consultant, the hepatologist and Professor Williamson, who is leading an OC research team at Imperial College, had a discussion and suggested I commence on rifampicin 150 mg a day.

Initially my blood results improved and I had my lowest bile acid result of 36 µmol/L, but at 26 weeks they started increasing again. I commenced weekly Doppler scans and the rifampicin dose was increased to 300 mg a day.

Finding ways of coping

The itch was as intense as ever. I spent most of my days on the sofa fidgeting and moving around to try to cope. My lack of appetite meant that I lost two stones (12.7 kilos) in my pregnancy. I would go to bed at about nine in the evening, but I wouldn't be able to sleep until perhaps five in the morning. This was my routine. I only left the house for appointments and sometimes would keep my pyjama top on under my jacket. I wasn't able to wear a bra for months.

My pregnancy seemed to last forever, but I kept focusing on reaching 36 ►

weeks, as the plan by the consultant was for labour to be induced at that point.

My bile acids continued to go up and down, but once I reached 30 weeks gestation I felt more relaxed –should my baby need to be born, then he would be safe. After 30 weeks my bloods continued to increase, from 80 µmol/L to 107 µmol/L and I was now on rifampicin at its maximum dose of 600 mg a day, along with the maximum dose of UDCA.

The weekly scans showed that the baby was growing well and the Dopplers remained normal.

Birthday

At 32+2 weeks my baby was born – a very traumatic day, but one that I now reflect on as an extremely special day, as it is my son's birthday. I had a normal Doppler that morning, but once I was home I felt tightening so I returned to the hospital and had an unreactive cardiotocograph (CTG) for three hours followed by a prolonged bradycardia, which resulted in a crash caesarean section. My baby boy was born weighing two kilogrammes with apgars of nought at one minute, five at five minutes and nine at 10 minutes and cord gases of 6.7 and 7.0. He spent three weeks in the neonatal unit with severe respiratory distress syndrome (RDS) and thrombocytopenia.

On the day I birthed my baby, on the maximum doses of medications, my bile acids had increased again to 126. I truly believe that my son just couldn't cope in my toxic body any longer; if it wasn't for the tightenings, I would not have gone into hospital for monitoring and my son would have been another stillbirth because of OC.

Evaluation

Looking back over my pregnancy and birth I can identify both the negative and positive points. One negative was that I was just one of a small number of people to develop severe early onset

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OC. I also did not enjoy my pregnancy, due to physical pain, discomfort and mental anguish. I remember how severely distressed I was on the day my baby was born because I understood everything that was happening. At that time I wished I wasn't a midwife.

The positives were that I had a diagnosis of OC and was treated accordingly and I found OC Support, who helped me to feel that I was not alone. On the day my baby was born, he was brought out as fast as possible and then received some of the best neonatal care in the country.

And of course, the biggest positive of the whole experience is that my baby boy was born safely. He is perfect in every way and I can't even remember what life was like before he came along.

Analysis

I am not a religious person, but I believe that everything happens for a reason. I can only think that my experience has strengthened me as a mother and as a midwife. I feel much more sympathetic to the women in my care, especially those who find themselves diagnosed with a condition that may put their baby's life at risk. In my view further research into this condition is desperately needed. I would urge you to read the factual paper in this issue of The Practising Midwife on OC (Chambers and Tuson 2012) to expand your knowledge base.

Conclusion and how things are now

Today, Alexander is a happy and healthy boy with no signs of being affected by hypoxia at birth. I am, however, still under the care of a liver specialist as my LFTs remain abnormal. I have just had a liver biopsy, as other investigations have so far failed to give an explanation as to why the ALT is still up and down and the gamma-glutamyl transpeptidase (GGT) keeps increasing. However, the liver biopsy didn't reveal anything.

I find that there seems to be a stigma attached to liver problems. If I tell anyone I have had to have a liver biopsy they seem to assume it is drinking related. I have even been asked multiple times by different doctors if I am a heavy drinker, but the fact is I do not drink any alcohol.

I have now returned to work and am trying to make work and family life balance. I'm also now a moderator for the OC Support forums.

Personal action plan

If we decide to have another baby, I would expect to get OC again and could cope. Although research suggests that I may not get it again, I would definitely ask to have Professor Williamson influence my care. I would have baseline LFTs and bile acid tests done before I got pregnant and again at booking. I would then request regular blood tests throughout the pregnancy. If I didn't develop OC I know I would feel like the luckiest person alive. **TPM**

Gemma Steele is a midwife

■ For further information go to www.ocsupport.org

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