Making sense of a miscarriage

March 1 2016, by Holly Cave

"Don't worry, pregnancy isn't an illness," said my midwife, smiling affectionately as I worried about my lack of morning sickness. She must have been well acquainted with the limbo of early pregnancy, the constant fluttering between hope and fear.

Two days later, doubled over on the toilet and clutching a hot water bottle as I watched dark clots of blood drip into the pan, it felt very much like an illness. I knew something was desperately wrong.

The largest lump of tissue – what I believe to be the yolk sac – was smaller than it felt in my heart. I searched for the embryo inside it until my clothes were stained with blood. I couldn't flush the toilet for an hour because I was sure that my baby was in there. Rationality had ceased to register through the distress.

The list of things I don't understand about my miscarriage seems never-ending. I don't know how old the embryo was when it stopped living. I don't know why it stopped living. I will never know.

"Why?" I asked myself. Again and again and again, as if it was a mantra that would take me back in time and stop it happening. Why? If someone could answer that, then at least I'd be able to grapple with another looming question: Will it happen to me again?

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"Miscarriages are so common – one in five pregnancies end up in a

miscarriage," says Arri Coomarasamy, a professor of gynaecology at the University of Birmingham. Empathy is soothingly evident in his voice as I come to the end of my story.

The one in five figure is often quoted. Sometimes it creeps up to one in four. This is because it's difficult to determine how many miscarriages take place. In the UK, miscarriage means the loss of a pregnancy during the first 23 weeks (any later and it is called stillbirth). But it often occurs before a woman even realises she's pregnant, and most of the time – 85 per cent – it is in the first 12 weeks of pregnancy.

That has given us clear social guidelines. The "12-week rule" warns against telling anyone you're pregnant until the end of the third month. It anticipates the risk of loss, even sets us up to tentatively expect miscarriage during the early stages of pregnancy, but this silence doesn't make it any easier if it does happen.

A recent survey of over 6,000 women who had had a miscarriage, conducted by the charity Tommy's, found that around two-thirds found it hard to talk about. The same number felt that they couldn't discuss their miscarriage with their best friend. A third didn't feel that they could even talk to the father about it.

Finding support remains a challenge for women experiencing miscarriage. Sharing was important for me – although saddening, I took comfort from the fact that friends of mine had also been through it. Like them, I would get through it. But we never talked about the experience itself, the physical process and the effects of miscarriage. Saying "I had one, too" seemed to be as far as it went.

So here goes. I was nine weeks pregnant when I started bleeding in the middle of a late night shift at work. The sight of that fresh, bright red blood was a sudden, vicious smack in the face. I pressed my hand over

my mouth until I could feel the outline of each tooth, as if to prevent anything else leaving my body. I bled; I cramped; I googled. The lady who answered the phone at the community midwife centre directed me to A&E. Later, my GP assured me that I was right not to go. "I can't think of a worse place to have a miscarriage," he said, his head in his hands.

The pain was bearable and the bleeding stopped after a week or so. My miscarriage was natural and complete, meaning that when I had a scan at the end of it, there was barely any evidence that I'd been pregnant at all. Nothing was left. Unlike many women, I didn't need medical management to complete the process. The staff who dealt with me were polite, straightforward and quietly sympathetic.

Other women are not so lucky.

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Lizzie Lowrie has had six miscarriages, all in the first trimester. The care she has received has been patchy. She's met people who've been "amazing", but she's also had to beg and cry down the phone to be admitted to hospital, and has turned up only to be congratulated on her pregnancy.

When she tells me about her most recent miscarriage, at ten weeks, I am shocked. She opted for a medically managed miscarriage, in which you take tablets that open the cervix to let the remaining tissue leave the body. "It was horrendous," she says. "It was so painful. And I was in this ward with other people doing the same thing… It was terrible."

Around 1 per cent of couples are affected by recurrent miscarriage, which in the UK is defined as the loss of three or more consecutive pregnancies.

Emma Benjamin has had several miscarriages, too, but still remembers the terror of the first. "They just sent me home and they didn't tell me anything," she says. "I came home bleeding – having the most awful period pains, I suppose – and not really knowing what to do or what was going to happen or how long I was going to bleed for. I knew nothing, literally nothing… I wasn't given a leaflet or anything. So it was horrible, it was really awful, because I suppose I didn't really know what was going on."

It's another side of the silence that surrounds miscarriage. But Benjamin and Lowrie both talk clearly and calmly about their experiences, and have become more open with each successive miscarriage. Lowrie tells me that for her husband and her the 12-week rule has "gone out the window".

"At first, very few people knew that I was pregnant," she says, "but then as the miscarriages went on we just made sure there were certain people close to us that knew… they tried to keep me sane when I was going through the pregnancy… It's just so hard breaking those two bits of news: I was pregnant and I'm not now. It's really hard to bring it into conversation.

"It is still quite a silent thing," she adds, "and I think part of it is that no one knows what to say."

Coomarasamy agrees that lack of support is a serious problem and that women who have an early miscarriage, and their partners, may need just as much help as those who have lost an older baby to stillbirth. "Whether it was this size baby or that size baby is irrelevant, and the psychological impact is not much different," he explains. "So I think there is a real need to understand how couples experience miscarriages. There's a real need to identify better ways of supporting the couples."

Lowrie and her husband now run a blog about childlessness called Saltwater and Honey. Of course, no one should ever feel they have to share their experiences – I have friends who wanted to keep their miscarriage private. But it does seem that it's becoming increasingly acceptable to speak out about miscarriage.

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Breaking the silence is crucial. Research has shown that one-third of women attending specialist clinics as a result of their miscarriage are clinically depressed. As well as depression and grief, it's been reported that both women and their partners experience increased anxiety for several months after a miscarriage. Post-traumatic stress disorder, obsessive–compulsive disorders and panic disorders have also been observed in research studies.

Once, this would have surprised me. Not now. Three months after my own miscarriage, I still struggle to see my experience in perspective. There are still days when I feel a shadow over me and a sadness in the pit of my stomach that won't go away. There are still days when a strange emotion surprises me with its stranglehold.

It's only after my conversation with Lowrie that I realise this emotion is grief. She, too, was confused, until a counsellor demystified what she was going through.

"I thought to grieve you had to have lost something you'd met – like a person that you had talked to – or you could grieve over a baby that maybe you'd held," she tells me. "I didn't know anything about grief… I didn't know whether I should leave that to people who had lost actual people, not a very, very tiny baby that you've never met."

Benjamin agrees: "I used to think, 'God, people go through so much

worse'… and I'd feel guilty for grieving… But in my head, I had planned when this baby was going to be born. So it was still as upsetting for me."

Part of this distress comes from that unanswered "Why?" Most women having their first or second miscarriage are told to put it down to one-off, unspecified genetic abnormalities in the fetus. It just wasn't meant to be. Yes, society likes fate. But women feel better if they get more accurate information, says Ruth Bender-Atik, national director of the Miscarriage Association. "The reason is that they have an answer, an explanation," she says, "rather than a huge question mark and a tendency to assume it's their fault."

Most women never get an answer, however, even if they are tested for possible explanations, because the science is sorely lacking.

"I think it's fair to say that miscarriage, despite being so common, despite having physical and psychological consequences to the woman and her partner, despite being a condition that demands quite a lot from the NHS, has not been researched well for a long time," says Coomarasamy. "But that is changing, I believe."

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The unspecified genetic abnormalities that are said to underlie most miscarriages have various possible causes. The risk of random genetic faults in the fetus seems to increase with the age of the mother: the chances of having a miscarriage rise from 9 per cent aged 20–24 to more than 50 per cent for women aged 40 and over. Beyond age, other risk factors associated with miscarriage include obesity, smoking, drug use, and drinking more than two units of alcohol a week or more than a couple of cups of coffee a day.

There are several other potential causes: abnormalities in the womb or

cervix, genetic faults inherited from the parents, hormone imbalances, polycystic ovary syndrome, various infections and so on. In the UK, tests for these possibilities are offered only after three consecutive miscarriages, whereas in many other countries the threshold is two.

Some women who've had a number of miscarriages have antibodies in their blood that seem to prevent the pregnancy embedding properly or cause blood clots in the placenta. This is called antiphospholipid syndrome, also commonly known as sticky blood syndrome, and it is the most important treatable cause of recurrent miscarriage. Low doses of aspirin, sometimes also the blood-thinning drug heparin, seem to help these women carry a pregnancy to term. It's the kind of hope many women and their partners cling to: that a cause will be found and an effective treatment will follow.

A blood test for these antibodies is therefore standard after recurrent miscarriages, but it's the answer only 15 per cent of the time. Half of all women who have tests are still left without an answer. Although Benjamin and her husband now have three children, a cause was never identified for her miscarriages. After two successful pregnancies in which she took progesterone, blood-thinning drugs, aspirin and steroids, she knows that it was more likely simply luck rather than targeted medical intervention.

Lowrie, still trying for her first child, has also tried taking low-dose aspirin, heparin and progesterone, but thinks she was probably only offered this cocktail of drugs because "they just didn't know what to do with me".

It's a familiar story to Coomarasamy. "There are a lot of people out there who are just putting patients on a bit of this, a bit of that," he says. "Statistically speaking, any patient who has had a miscarriage previously – almost all patients who have had a miscarriage previously – the odds

are in their favour in terms of having a normal pregnancy next time round, no matter what one does. So if they happen to be popping a pill it may have nothing to do with it. In fact, statistically speaking, they were going to carry that baby to term anyway."

While aspirin increases the chances of a successful pregnancy for the minority of women with sticky blood syndrome, it had no significant effect in clinical trials for other women at risk of miscarrying. And following years of debate, the results of the PROMISE trial announced in November 2015 showed that progesterone supplements did not prevent early miscarriage for women with unexplained, recurrent losses.

A number of other trials continue to investigate potential treatments. The RESPONSE trial is testing a medicine called NT100 to find out if it can improve the chances of a successful pregnancy without serious side-effects. The TABLET trial is looking into the role that thyroid antibodies may play in women with unexplained miscarriage, and whether the drug levothyroxine may help. Lowrie is one of those waiting to hear if she is eligible to take part.

Lots of women seek out such trials, keen to be involved. Of Coomarasamy's patients at Birmingham, 60–70 per cent take part in clinical trials being carried out there, and often the research team finds recruits through other avenues, such as Facebook campaigns. They are all looking for answers, hoping for a breakthrough. But it may be that to understand miscarriage better, we need a new approach.

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Jan Brosens is a professor of obstetrics and gynaecology at the University of Warwick. He agrees that our current knowledge is too thin to help many people after recurrent miscarriage and says the current tests available are mostly a waste of time. "[For] the vast majority of couples

that you see in clinic, you can test until you're blue in the face and you will find nothing," he says. "But more importantly, even if you have a patient where you have a positive test, you will find that same positive test in at least 50–100 women who don't have a history of miscarriages."

In other words, the tests are nowhere near specific enough to identify what is causing recurrent miscarriages. Brosens thinks we will make more progress if we change the way we think about miscarriage.

"The problem I face when I see patients is that the vast majority come with this narrative that has been imposed upon them – and which they defend – which is that miscarriages are your body rejecting the pregnancy, that this is a complete failure," he says, sadly.

Instead, he is keen to emphasise that a successful pregnancy begins with the start of a period – an event that so many women regard merely as an annoyance or, at worst, the uncomfortable end to another month of trying to conceive a baby.

But consider it differently, and the period is just the beginning, as the old womb lining disappears and a completely new one begins to grow. Brosens's research with Siobhan Quenby at Warwick's Biomedical Research Unit in Reproductive Health suggests that the womb lining plays a major role in determining whether the next pregnancy succeeds.

Most if not all human embryos have some chromosomal abnormalities. The range of variation runs from embryos with errors in a couple of cells right up to ones that are so unstable they are known as "chaotic". The cells of the womb lining, the endometrium, go through a process called decidualisation in response to the pregnancy hormone progesterone, which makes them able to recognise genetically poor embryos and prevent implantation so that pregnancy never begins.

But if the womb lining isn't suitably prepared, it may prevent healthy embryos from implanting – or do the opposite. Brosens and Quenby's research has found that in women with recurrent miscarriage, the womb lining is often super-receptive but unselective, meaning that it allows genetically doomed embryos to implant and grow. These women may get pregnant fairly easily, but the pregnancy never truly has a chance of succeeding.

"In essence," Brosens tells me as firmly as his friendly Dutch lilt allows, "I completely and utterly dismiss the current view of miscarriages."

The idea that something has "gone wrong" in your pregnancy? No. The feeling of guilt that you must have done something wrong, despite sticking to all the rules of pregnancy? Pointless, because the outcome of your pregnancy was most likely determined at that moment of implantation.

Brosens is convinced that this new perspective will eventually lead to an uplifting advance: being able to predict who is at risk of miscarriages, even among women who have never been pregnant. When cells taken from the womb lining of women who have experienced recurrent miscarriage are cultured in the lab, "the behaviour of the cells is very, very different [compared to] control patients," he says. This provides a new starting-point for developing diagnostic tests and even treatments to make recurrent miscarriages far less likely.

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Today, after just one miscarriage, the statistics tell me that I have an 80 per cent chance of my next pregnancy being successful. Regardless, I have been worrying that my miscarriage was the result of something that might make me prone to it happening again. I simply don't know, and it's the same for most women experiencing miscarriage, whether their first

or their fifteenth.

The wonders of modern science have accustomed us to medical explanations and diagnoses. The women I've spoken to – Emma Benjamin, Lizzie Lowrie and some of my friends – share similar feelings of frustration. We expect that doctors will find out what is wrong with us and give us something to treat that problem. We think we will feel better if that happens.

For the small percentage of women whose every pregnancy has ended in miscarriage, the question of why looms particularly heavy over their trauma. While Lowrie hasn't given up hope of having a child of her own, she has accepted that it may not happen.

"I don't think there is always a resolution, but sometimes you've got to live with that," she says. "Life isn't neat. We don't always have answers."

I don't have an answer, and I know I'm not going to get one any time soon. So for now, I'm going to try and stop asking "Why?"

One tiny life has ended, but mine goes on.

More information: Stef P. Kaandorp et al. Aspirin plus Heparin or Aspirin Alone in Women with Recurrent Miscarriage, *New England Journal of Medicine* (2010). DOI: 10.1056/NEJMoa1000641

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