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The Conversation

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Desperate couples are misled by only positive reports of IVF

Reflecting on her imminent departure as head of the Human Fertilisation and Embryology Authority, the body that regulates IVF and fertility services, Lisa Jardine said [in an interview](#) last week that “nobody wants to run stories about the people who go through IVF for nothing.” She’s right.

There’s a paucity of stories about couples that have been through the IVF treadmill and still remain childless (or fertility treatments that [don’t work for most](#)). Hardly anyone bears witness to the spiralling cost of IVF treatment and the enormous sacrifices that couples are prepared to make. When did you last see a TV medical documentary that showed the gruelling failed treatments that cost thousands, and coupled with debt from having to remortgage? Or a final haunting shot of a beautifully decorated but uninhabited child’s nursery?

Instead, as Jardine said: “The stories are always exciting. The stories about multiple births are always about beautiful babies.” These stories often go hand-in-hand with has been described as a “cycle of hype”. Headline after headline promise hope, which also parades “success rates that the industry knows it cannot match”. So shouldn’t a regulator investigate this?

Over-hyped

I recently took part in a debate on BBC Radio 4’s Woman’s Hour about the reporting of IVF technologies and a recent [story in The Times](#) which had carried the headline: “New IVF technique could give 78% chance of success”. The article reported on [a retrospective](#) study in a peer-reviewed journal that described the use of time-lapse imaging to spot embryos at high risk of genetic abnormality – one of the reasons why embryos fail to implant – or miscarriage during IVF. The figure, which wasn’t included in the study (but later quoted by the researchers after all the mothers they were studying had given birth), was published widely in papers including the Guardian and the Daily Mail.

Simon Fishel, one of the co-authors of the paper and managing director of the UK’s largest private infertility clinic, the Care Fertility Group, was also in the studio along with Nick Macklon, a professor of Obstetrics, who’d [written to The Times](#) berating them for over-hyping the findings of Fishel’s paper.

While there was widespread excitement about the 78% figure, the limitations - size of the study, how it compared to standard techniques and that it came after the study was published - took a back seat. As Jardine said, she would be suspicious of any clinic that “claims their success rates are greater than 60%”.

PR involvement

Fishel said he had approached the science PR agency, the Science Media Centre (SMC), to help publicise the paper. The paper’s authors declared no financial or commercial conflicts of interest. But it’s a stark new world of corporate science where the owner of the largest private infertility clinics in the UK, who could gain financially from the publicity, approaches an agency to sell an overhyped “breakthrough”.

As Macklon pointed out during the radio debate, the research was in its earliest preliminary stages and needed further evidence – the gold seal of approval that is a randomised clinical trial – before a firm conclusion could be drawn. Fischel countered that desperate couples couldn't wait for these trials and by extension, evidence-based medicine. Instead practitioners should rely on "shared clinical experience" and "logic". An assertion [he later repeated](#) for couples self-funding treatment.

In this new world of spin, corporate science uses corporate spin to attract unsuspecting and hopeless couples, who then cut out articles from The Times and visit their GP, hoping. The Science Media Centre has said it doesn't issue press releases (which I said it did on the programme) but "briefings"; rapid reactions and expert commentary. The record stands corrected, but for whom?

Big business

There is an important ethical issue at stake here. Fertility is very big business. Care Fertility's most recent accounts show [profits rose](#) from £2.37m to £4.1m between 2011 and 2012. At its Nottingham centre, prices in 2012 were roughly £2,850 for a standard IVF cycle.

Even IVF pioneer Robert Winston is tired of this inequality. He has said that women are being charged three times the actual cost of their treatment and has [accused private fertility clinics](#) of "exploitation".

When asked whether she had any regrets during her time as chair of the HFEA, Jardine said that as a communicator she regretted that she "hadn't been able to reach out to the public to explain to them the drawbacks of IVF as well as its wonderful hope".

So here's the question: when will the HFEA see fit to urgently investigate the business of IVF? For a start, perhaps it could use some of the money it also spends on corporate PR to do this. Until then desperate couples will continue to spend all their money on a hope, without knowing the real odds they face.