



**NEWS RELEASE Under embargo until: 00.01am 4 November 2024**

**New research reveals infertility-related trauma is more common than previously recognised**

**National charity Fertility Network UK calls for more trauma-informed healthcare and counselling interventions**

Infertility-related trauma is more common than previously recognised, according to data published today by national charity Fertility Network UK, ahead of the launch of Fertility Week 2024.

The survey found fertility patients reported that their experiences of trauma are compounded by poor care provision, highlighting the importance of providing trauma-skilled fertility healthcare. This recognises that patients may be affected by adversity or traumatic events whether fertility-related or not, and that all care should create safety and trust for patients, so preventing and reducing the impact of these events.

This research was co-produced by Fertility Network and lead researchers at Cardiff University, Cardiff Metropolitan University and Queen's University Belfast, in association with the British Infertility Counselling Association (BICA).

The research analysed data from 590 respondents from across the UK and Ireland, who self-reported their traumatic experiences linked to various infertility events.

A total of 41% of respondents met criteria for post-traumatic stress disorder (PTSD) and complex PTSD, according to the International Trauma Questionnaire (ITQ, 32% of respondents with complex PTSD and 9% with PTSD). This is not necessarily representative of all who experience infertility, but only of those responding to the survey.

While some patients reported positive experiences, respondents noted the care they experienced during their fertility journey in some cases caused or exacerbated trauma. Only a minority of respondents (16.1%) reported healthcare professionals (HCPs)

discussed infertility-related trauma with them, or put in place support to help them cope with infertility-related trauma (27.6%). A majority (61.2%) reported aspects of the fertility care they received made trauma worse.

The research gives testimony to patients' traumatic experiences of events along their infertility journey.

Patients' comments include: *'No one has ever offered me support with the impact this has had on my mental health or even acknowledged it is hard.'*

*'...after a successful round of IVF our child was stillborn. I can't really put into words the pain and trauma of losing our baby, but we then had to face further fertility treatment, something I feel has been completely overlooked.'*

*'My journey and failure to have children left me with PTSD and I often contemplated suicide.'*

Lead researcher Dr Sofia Gameiro, Cardiff Centre for Reproductive Research, Cardiff University said, 'Participants described a wide range of medical events as triggering traumatic experiences which were in many cases compounded by the care context.

In many cases, it was the repetitive or cumulative effect of distressing events that seemed to exacerbate the traumatic nature of these, alongside social triggers.

While some respondents reported positive, skilful and compassionate care, it was clear that over 60% highlighted aspects of the care they received caused or amplified trauma.'

Examples of care experiences exacerbating trauma included: a lack of empathy or acknowledgment of distressing experiences; poor information provision, such as dismissive or conflicting advice, or no forewarning nor explanations about negative treatment outcomes, when sharing bad news; and insensitive and unsupportive care from staff.

Positive experiences of trauma-skilled care described by patients included: better information to manage expectations of success; timely counselling referrals; explanations of the emotional aspects of treatment; and acknowledgement of reproductive experiences as traumatic, particularly in the context of miscarriage.

Trauma-informed cognitive behavioural therapy (CBT) counselling and the gold standard EMDR (eye movement desensitisation and reprocessing) therapy are recommended treatments by the World Health Organization (WHO) and National Institute for Health and Care Excellence (NICE) guidelines.

Dr Gameiro also noted: 'The research suggests there are specific reproductive and treatment events that are most associated with traumatic experiences, such as one or more unsuccessful IVF cycles, ectopic pregnancy, miscarriage and baby loss, complicated birth, stillbirth and unsuccessful fertility treatment as a whole.

The 'waiting' nature of IVF was also perceived by patients as having had an impact, as did the invasive, sometimes painful treatment procedures creating a perception of lack of control over the process and over their bodies.

Other factors contributing to participants' distress included lack of access to NHS-funded care, high cost of fertility treatment and social and workplace triggers, such as children or baby-related jobs.'

Sharon Martin, interim chief executive of Fertility Network UK, said: 'Although many of us working with or supporting fertility patients are acutely aware of how distressing a fertility journey can be, it is shocking and deeply concerning to see the high levels of infertility-related trauma that we suspected, confirmed in this research.

Thanks go to all those patients who shared their experiences. Many said they felt heard and validated in sharing their hidden, unspoken fertility-related experiences, sometimes for the first time.

Looking to the future, this research will raise awareness and understanding of the extent of infertility-related trauma among patients for all those working in this sector. We will continue to work with our academic partners and all our partner organisations, to help create collaborative recommendations for improved trauma-skilled care for fertility patients, including the availability and equitable access to more NHS-funded fertility treatment and timely signposting to specialist trauma-focussed interventions.'

Gerry McCluskey, specialist BICA fertility counsellor and trainer said: 'Fertility counsellors have become increasingly aware of the high-level trauma experienced by many in their pursuit of parenthood.

It's not an inability to cope, or weakness, but the impact of enduring, highly distressing experiences. (C)PTSD and other levels of trauma are treatable, but left untreated they can adversely impact birth and parenting experiences, not to mention work and life experiences.

There is a greater need for the fertility industry as a whole to prioritise the emotional and mental health aspects of fertility care, train all staff to become trauma-skilled, and create robust and meaningful access to psychosocial care where trauma can be identified, signposted and worked on.'

Anita from Surrey was diagnosed with complex PTSD after failed IVF and an ectopic pregnancy. Anita says: 'I was having regular lengthy panic attacks in the middle of the night, experiencing suicidal ideation and complete dissociation with my emotions and life. We stopped treatment and a year later I found myself in a psychiatric hospital being diagnosed with complex PTSD. In hindsight, after the ectopic I wish someone, such as a medical professional, had spoken with me about the risk of PTSD after such events and assessed my mental health... they may have identified that I was actually unwell and

should not be going forward for another round of IVF because it was further damaging to my mental well-being.’

Julia Chain, chair of the Human Fertilisation and Embryology Authority (HFEA), said: ‘This report shows just how crucial it is for patients to receive quality support at all stages of fertility treatment. Undergoing treatment can be a highly emotional experience and, as set out in the law, licensed clinics must offer counselling to all patients before their treatment begins.

‘Our Code of Practice sets out that clinics must have a patient support policy, as well as provide the opportunity for proper counselling throughout the treatment, donation, or storage processes, and afterwards if requested. All patients, donors, and their partners should be treated with sensitivity and respect and supported through all aspects of their treatment and, in particular, that patients may be suffering distress at any stage and need additional support.’

Stuart Lavery, consultant in reproductive medicine, divisional clinical director women’s health, University College Hospitals NHS trust, and member of the British Fertility Society, said: ‘The research by Gameiro and colleagues highlights the important and previously under-researched subject of trauma related to infertility. Alarming, 41% of the study respondents met criteria for a diagnosis of PTSD.

Perhaps one of the most concerning findings is that the patient’s experience of trauma was frequently compounded by the treatment they received. This research should serve as a wake-up call to all professionals involved in fertility treatment to not only be aware of patient trauma but to carefully examine their own care pathways to see what can be done to improve the experience of their patients.’

This research will be published as a scientific research paper in the near future.

For anyone affected by trauma in infertility, details of support for patients are available on the Fertility Network UK website [www.fertilitynetworkuk.org](http://www.fertilitynetworkuk.org)

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**Notes to editors:**

Patients’ responses about their experiences are at the end of this press release, after notes to editors. For interviews, media volunteers and case study details, contact Catherine Hill, communications manager on 07469-660845  
[media@fertilitynetworkuk.org](mailto:media@fertilitynetworkuk.org)

1. Respondents to the survey were predominantly female (98%), white (94.7%) and heterosexual (94.6%). Just under half of respondents (46.1%) of respondents did not have children. Nearly two-thirds (64.6%) were currently trying to conceive. On average, respondents had been trying to conceive for 3.5 years and had completed more than four IVF cycles. 62% were resident in England; 11.7% in Northern Ireland; 5.3% in the Republic of Ireland; 10.7% in Scotland and 6.4% in Wales.
2. 865 consented and 590 (final sample) reported a traumatic experience or filled the ITQ questionnaire. Fifty-three (9%) participants met criteria for PTSD, 189 (32%) for CPTSD, and 242 (41%) for any diagnosis. Correlates of (C)PTSD were not having children, strength of child desire, currently trying, time since traumatic experience, and other reproductive events, specifically unsuccessful treatment, abortion, miscarriage, recurrent miscarriage, and health complications after birth.
3. Around a third of respondents reported an infertility-related traumatic experience had occurred during the last year, and over half of respondents (54%) in the last 1 to 5 years.
4. Respondents were more likely to report trauma if they did not have a child.
5. PTSD: Post-Traumatic Stress Disorder (PTSD) is a mental health condition that can develop after experiencing or witnessing a traumatic event. Symptoms often include flashbacks, nightmares, severe anxiety, and intrusive thoughts, and they can significantly impact an individual's ability to function in daily life without proper treatment. Symptoms of PTSD can mirror those of anxiety or depression; however these are specific mental health issues that generally manifest without exposure to a traumatic event.
6. The clusters of symptoms required for a PTSD or Complex PTSD (CPTSD) diagnosis indicate a clear overlap with the well-documented symptomatology reported by people with fertility problems or undergoing fertility treatment. These include avoidance of traumatic reminders (people, places, situations), changes in cognitions and mood, problems in affect and regulation (for example: anger, emotional numbness), beliefs about oneself as diminished, defeated or worthless (with feelings of shame, guilt or failure related to the traumatic event), and difficulties in sustaining relationships and in feeling close to others. CPTSD tends to occur more commonly after chronic, repeated, or prolonged traumas that are difficult to escape from, which also provides a good characterisation of experiences of fertility care, that tends to be prolonged and with recurrent experiences of unsuccessful cycle(s).
7. The International Trauma Questionnaire (ITQ) is a validated self-report tool designed to assess symptoms of PTSD and Complex PTSD, based on the criteria of the 11th Edition of the International Classification of Diseases. The ITQ helps clinicians gauge the presence and severity of trauma-related symptoms, facilitating more targeted treatment planning.

8. Eye Movement Desensitization and Reprocessing (EMDR) is recognised by the WHO as the gold standard for Complex PTSD. However, it is not widely available in the NHS. EMDR is a structured therapy that helps individuals process traumatic memories. It is recognised by the WHO and the NICE for its effectiveness in treating PTSD by using guided eye movements or other bilateral stimulation to help the brain reprocess distressing memories, reducing their emotional intensity.

9. Fertility Network UK is the nation's leading patient-focused fertility charity. We aim to provide fertility patients with free and impartial support, resources, and information. We advocate for patients' needs via educational projects, awareness campaigns, and the media, and we are key actors in developing policy and practice within the sector.

10. Fertility Week is 4-8 November 2024; #FertilityInMind focuses on the mental health impact of infertility and its treatment. Fertility Week seeks to change perceptions, provide support and raise funds for everyone struggling with fertility issues.

**Respondents' comments include:**

*'No one has ever offered me support with the impact this has had on my mental health or even acknowledged it is hard.'*

*'[Embryo] transfer failed. No support given. No offer of counselling. We were devastated after each failed round and clinic offered absolutely no support.'*

*'Egg collection procedure was extremely traumatic with a complete lack of understanding and support from some of the medical staff.'*

*'This was my final embryo and it did not survive the thaw. The phone conversation that ended that cycle was horrendous. It felt so abrupt and I was too upset to ask any questions.'*

*'... this was the most important thing to me in the world and it hadn't worked, and nobody could be bothered to pick up the phone to tell me why.'*

*'...after a successful round of IVF our daughter was stillborn. I can't really put into words the pain and trauma of losing our baby but we then had to face further fertility treatment, something I feel has been completely overlooked.'*

*'The procedures are painful and traumatic in themselves. Having to continue with suppositories and a pregnancy test while bleeding extremely heavily was traumatic.'*

*'I cannot have a smear test or sex without a trauma response as a result.'*

*'My journey and failure to have children left me with PTSD and I often contemplated suicide.'*

**Workplace:** *"Falling pregnant after ICSI, seeing heartbeat on scan at 6 weeks then returning at 8 weeks to be told no heartbeat and that I would need to come off*

*medication to miscarry. Meanwhile my school got the Ofsted call, my department were picked for the 'deep dive' and I had to spend a day with the lead inspector terrified I was about to begin the bleed”*

*‘My ectopic pregnancy (...) I had concerning symptoms which I felt were "ignored" by several healthcare professionals until I became very sick and was rushed for emergency surgery due to fallopian tube rupture and internal bleeding. I felt so ill and so scared and angry that I wasn't listened to. I have struggled hugely with mental health since.’*

*‘My husband suffers from crippling OCD [obsessive compulsive disorder], anxiety and depression after our infertility journey. He was diagnosed with azoospermia and the long waits for answers resulted in his mental health declining.*

*‘My journey and failure to have children left me with PTSD and I often contemplated suicide.’*

**Positive comments:**

*‘Had EMDR therapy for trauma and support from mental health midwife while pregnant as found that a very anxious time.’*

*‘The medical team looking after me have been incredibly supportive and I have felt lucky to be under their care.’*

*‘... the nurses discussed with us that miscarriage was a traumatic experience, especially on top of our fertility problems. The nurses were very empathetic and offered us both counselling.’*

*‘My husband and I were given very good counselling and information packs about all the ways in which we may find the experience traumatic.’*