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## **Let down: lack of support for fertility patients before, during and after treatment**

Three quarters of individuals receiving counselling for fertility problems say it is helpful in dealing with the associated high levels of psychological distress, suicidal feelings and relationship breakdown experienced yet only a minority (44 per cent) of people affected do receive counselling and the majority of these (54 per cent) have to fund some of it themselves, according to a national survey from patient charity Fertility Network UK.

The survey, conducted in association with Middlesex University London, assessed the impact of failing to conceive and the subsequent impact of fertility treatment on both women and men. It found levels of emotional distress were extremely high: approaching half of all respondents reported, on average, feeling sad, out of control, frustrated, helpless, fearful and worried nearly all of the time. 90 per cent of respondents reported feeling depressed and 42 per cent of respondents experienced suicidal feelings. Those who had unsuccessful treatment reported greater distress as well as more frequent suicidal thoughts.

70 per cent of respondents reported some detrimental effect on the relationship with their partner; 15 per cent said this relationship was strained or ended. The vast majority of respondents (88 per cent) experienced some detrimental impact on relationships with partner, family and/or friends.

Approaching three-quarters of respondents (73 per cent) said they would have liked to have counselling if it was free. However, only 44 per cent did access counselling, despite it being mandatory for fertility clinics to offer counselling before treatment (this mandatory counselling is not necessarily free). Of the people who did access counselling, 36 per cent had private counselling only, 46 per cent had free NHS counselling and a further 17 per cent had to top up NHS counselling with additional private counselling.

The majority of people who had counselling found it helpful (75 per cent). The main reasons for people not finding counselling useful were due to the wrong timing or focus of the

counselling, or because it was seen as a tick box exercise or something they had to do to receive treatment.

Other avenues of emotional support are also inaccessible for most. Half of the survey respondents (50 per cent) said they would have liked to attend a local peer support group if one had been nearby; but just 20 per cent of individuals could access help in this way.

Susan Seenan, chief executive of Fertility Network UK said: 'Much more needs to be done: fertility patients are not receiving the emotional support they need before, during and after treatment. Given the high levels of psychological distress and people experiencing suicidal feelings, especially among those who have unsuccessful treatment outcomes, access to funded counselling is crucial.'

It is vital that such support is available at an appropriate time and has an appropriate focus in order to maximise effectiveness. Those who have unsuccessful treatment outcomes need specific support, as well as couples experiencing relationship strains.

'Access to local peer support groups is also critical: that is why Fertility Network UK is working to increase the numbers of support groups across the country and is taking forward a project to both provide support and encourage fertility clinics to provide additional support to those who have had unsuccessful treatment.'

Fertility patient Laura, 29, said: 'The timing of counselling is so important. Flexibility and timelines have been a crucial part of our treatment. What has been particularly beneficial has been the timeliness of the appointments; also we have found it useful to be able to control the length of time between each appointment. The time following each session can be difficult as you are still both processing the information and working through emotions. Hence it was really useful to be able to have them close when we needed and then a longer break when needed too. That said, we have had to search, fight and stress to get this. The process is NOT at all simple or straightforward.'

What needs to be recognised is the emotional impact of infertility. Even prior to committing to fertility treatment such as IVF, couples are already emotionally sore, the relationship already tested. To then have to face the intense hope and disappointment, amidst the stress of managing appointments and daily injections, would be incredibly difficult without emotional support.'

Anne Chien, infertility counsellor and chair of the British Infertility Counselling Association (BICA) said: 'It is known that high levels of emotional distress can be experienced by some individuals who are having fertility treatment and that it can impact on their relationships with partners, family and friends. Counselling is an integral part of fertility treatment and, from this survey, many patients recognise the benefits of counselling. However, the results also highlight that despite many respondents identifying a need for counselling, for many patients it sadly remains difficult for them to access, and availability seems variable.'

Clinics have a duty of care to their patients and the Human Fertilisation and Embryology Authority makes it clear that the offer of counselling is a mandatory part of this care. Infertility can be very stressful and can potentially have a longer term emotional impact on some, therefore patients should expect to have access to counselling as a part of this process.

Patients should not only be made aware of the availability of counselling; clinic staff also need to consider how it is offered and the value and benefits of it should be emphasised. Everyone having treatment should be able to see a specialised infertility counsellor through his or her licensed clinic before, during or after any treatment.'

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Notes to editors:

1. The full report *Fertility Network UK Survey on The Impact of Fertility Problems 2016* by Dr Nicky Payne [N.Payne@mdx.ac.uk](mailto:N.Payne@mdx.ac.uk) and Prof Olga van den Akker is available to download at [www.fertilitynetworkuk.org/news-media/news/](http://www.fertilitynetworkuk.org/news-media/news/)

There were a total of 865 responses (from predominantly women). The average age of respondents when starting fertility treatment was 32.5; typically respondents had been trying to conceive prior to this for 4.4 years.

2. All fertility clinics licensed by the Human Fertilisation and Embryology Authority have to offer patients an opportunity to talk to a counsellor about the implications of their suggested fertility treatment before patients consent to the treatment. However, there is no legal or statutory requirement other than to make counselling available in this manner: how many sessions, the cost or not of the therapy, and whether counselling is available during or after treatment is at each clinic's discretion.

3. Fertility Network UK provides practical and emotional support, authoritative information and advice for anyone experiencing fertility issues. The charity works to raise the profile and understanding of fertility issues and to push for timely and equitable provision of fertility treatment throughout the UK.

4. Fertility Network UK provides a free and impartial Support Line 0121 323 5025

5. Fertility Network UK supports people. We rely on voluntary donations to continue our vital work. You can donate now by visiting [www.justgiving.com/infertilitynetwork](http://www.justgiving.com/infertilitynetwork)

6. Specialist fertility counsellors can be accessed via the British Infertility Counselling Association website: [www.bica.net](http://www.bica.net) BICA seeks to continually raise the standard of counselling support offered to people affected by fertility issues and to help them access the right help.