

The Importance of Clinics Creating a Culture of Support

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For those struggling to conceive, trying for a baby can be an exhausting, heartbreaking and stressful time, full of ups and downs and feelings of hopelessness, failure and grief.

This makes the process a rollercoaster of emotions, where those involved struggles to deal with even the simplest daily tasks without it reminding them of wanting a baby.

Many feel their life is on hold (they avoid changing jobs, booking holidays, planning an events), feel jealousy towards others who are pregnant and struggle to remain hopeful that

They feel grief every month that they are still not pregnant, the grief for a life they want that includes children. They feel that their life is at a standstill while everyone around them is moving forward. They are putting off doing things 'in case I get pregnant' and are putting extreme pressure on themselves and their relationship by their only focus being on getting pregnant.

Research shows that women battling with infertility experience the same level of depression as women with cancer, HIV, and heart disease, and a shocking 42 percent respondents reported feeling suicidal at some point in a recent survey by the Fertility Network.

If you apply that percentage to the number of women going through IVF in a year that would mean there are potentially 21,000 women feeling suicidal due to infertility every year. And that number doesn't include those that are not currently having treatment or can't afford to have treatment.

It shows the huge emotional trauma caused by infertility and explains why these women may struggle with the intensity of treatment, and why providing a high level of emotional support is critical for helping patients cope whilst going through fertility treatment.

The 2016 Fertility Network survey (of over 900 women going through IVF) found that:

Respondents felt on average sad, frustrated and worried nearly all of the time.

- 42% experienced suicidal feelings (occasionally, sometimes, often or all the time) as a result of fertility problems and/or treatment.

This is up from 20% in the previous survey done in 1997.

- Those most in danger of experiencing high levels of distress and suicidal feelings were those who had unsuccessful treatment, who spent longer trying to conceive, who experienced some relationship strains and who had less support from friends and family and their employer.

- 70% reported some detrimental impact of fertility problems and/or treatment on their relationship.

- 28 % of respondents received help from Fertility Network UK and 45% from another agency or web resources.

- Only 17% attended a support group but 52% would have liked to attend had there been one.

- 52% of respondents sought advice on changing aspects of their lifestyle and 93% actually made lifestyle changes.

This survey highlights the real emotional effect of infertility, its wide-reaching impact and how patients want to take control in any way they can.

Another recent survey by the HFEA of over 1000 patients and their partners on the service they received at their clinic, found that:

- Improving patient satisfaction is likely to have the greatest impact on overall satisfaction with the fertility process as a whole.

(Pilot National Fertility Patient Survey 2018, point 1.2.15)

- Many spoke highly of the healthcare professionals, yet some felt that the healthcare professionals lacked empathy and that the process felt rushed.

(Pilot National Fertility Patient Survey 2018, point 4.2.11)

- "Some professionals lacked empathy in difficult situations which made us feel like just a number in the system rather than real people." (point 4.2.13)

It shows that whilst care in clinics is good, there is still work to do in increasing the emotional support they offer patients and their understanding of the emotional impact on patients and how they can better support them.

I have also been running my own survey in my support community on emotional support in clinics. The initial feedback is already showing some interesting results:

- Respondents rated the support they have received from clinics as an average of 5 out of 10. 10% rated the support at 0, and another 10% rated it 2.

- 63% of respondents felt that their clinic doesn't have a culture of support that is followed by all members of staff.

- 73 per cent want stronger connections to social programs and 66 per cent want their clinic to provide a community network where they can join.

- A lot of the feedback has been about wanting to be treated as a person rather than a number.

Some quotes from patients in my survey:

- "Please don't treat me like one of the herds. Realise that this is horrifically painful. Realise that this is impacting on every single part of our lives - jobs, relationships, family and friends. They are the ones who keep the next door open for the keys, so

don't create barriers at any point.”

- “We know that you see this day in and day out but for us this is totally alien and all very new to us. Please take this into account when speaking to patients and don't assume prior knowledge or make comparisons.”

- “Listen more, make more time for your patients. We are all different and feel different things at different times. It may be easy for you reading off what our follicle sizes and womb lining is but each one of those words means so much. I know you're busy and over stretched but just treat us like a friend and not a number.”

All this research shows how tough infertility and treatment can be. When going through treatment patients spend a lot of time at their clinic, and control of their fertility is taken out of their hands and in to those of their consultant. Unfortunately, it can be a long road to achieving their dream of having a baby, and it's important that the time they spend with you is positive and supportive, and they feel comfortable with the treatment they are having. Patients feel overwhelmed and out of control, they want to know that they have put their future happiness in the right hands. Clinics shouldn't assume they are offering enough emotional support by just offering access to a counsellor. Patients spend a lot of time at the clinic with various members of staff, and their heartache doesn't end when they walk out of the clinic's doors after their appointment.

Clinics need to recognize that if they support patients every time, they communicate with them, they will feel more valued, feel more confident in the clinic, cope.

What is a Culture of Support?

- Empathic patient-centred care – putting yourself in to the shoes of the patient, really listening to their needs and adapting your care and service to support them.

- A whole team approach to support – including all members of clinic staff, from receptionists through to the consultants.

- Every point of contact, for every patient, with every staff member is to be supportive.

- Everyone understands their responsibilities in supporting patients – what it includes and why it is important.

- Encouraging patients to access additional emotional support and signposting where possible.

How to create a Culture of Support?

- Provide staff training on empathy and patient support to ALL members of staff. Also provide refresher training and inductions to new staff on emotional support.

- Include empathic qualities when hiring staff and include in staff KPIs.

- Regular team meetings covering emotional support and feedback from patients. Consistently highlight the importance of patients having a positive and supported experience in every point of contact with the clinic.

- Robust feedback process on patient experience, including emotional

support, with clear process for acting on feedback.

- Offer a range of support services to give patients choice in which is right for them.

- Create strong links to GPs so that support starts earlier in the process.

- Create links to trusted holistic therapists.

- Provide supportive documents to patients to help them cope with treatment.

What difference will it make to patients?

- They will have a better treatment experience, which will help them cope better with treatment and the outcome (positive or negative).

- They will have more trust in the clinic and the treatment plan.

- They will feel comfortable to challenge and question treatment choices.

- They will feel happier, more in control and less overwhelmed.

What difference will it make to clinics?

- Higher retention rates – patients who have had a good experience are more likely to stay with their clinic for further cycles.

- Higher conversion rates when you show potential clients that you prioritise their emotional health from the very start of the process.

- It demonstrates they are working in line with the HFEA code of conduct.

- Higher success rates due to patients being in a better emotional state throughout treatment.

- Good reputation and referrals.

- Staff feels supported and valued.

- It gives them a point of difference over other clinics now that success rates

When emotional support in clinics is done well it makes a huge difference to the patient...

“My nurse Helen, she was AMAZING, really down to earth yet always professional, always there for a chat on the end of the phone or in person & there to Explain the process and test that before the IVF treatment my mental health is in top level”

“Our consultant has been amazingly supportive during this journey. He has always been available to ask questions, has done my last few egg collections, offered to do embryo transfers, was really happy when we were pregnant, gave us a huge hug after our first scan. Supported us and checked up on us after our miscarriage and rang me with the results of the genetic testing.”

“The best nurse by far was Katie. This lady is amazing! She genuinely makes you feel like she gets it, not just the having to have IVF to create a family but also the using a donor to conceive. She has a brilliant ability to make you feel like she really gets your heartache and just how hard it can be being infertile. Her empathy and understanding always put both me and my husband at ease. She was never too busy to listen. She would always do whatever it took to make our lives easier. Her get it done and put the patient first attitude is fabulous. Her sense of humour is brilliant she managed to make me smile even on the hardest of days and that is extremely important. The support she gave us as a couple was outstanding. Everyone facing infertility needs a Katie in their life. If the clinic was full of Katie’s the emotional support would be amazing.”

Emotional support isn’t one size fits all, all patients cope in different ways and are affected by infertility in different ways. People obviously also feel different the longer their fertility journey goes on for, so they will need supporting in a different way to those who are just about to treatment.

It isn’t enough to just provide access to a counsellor, patients should be encouraged to access the support that is right for them and should feel supported by all staff at the clinic at every point of contact they have with them.

With success rates remaining fairly static, and add-ons not yet having enough evidence to prove they positively impact chances of success, clinics need to differentiate in other ways, and focussing on emotional care is definitely the way forward. It has a positive impact on the experience of patients, staff morale and clinic reputation, conversion and retention, so is definitely worth investing in.