When Should Infertility Treatment Counselling Become Infertility Bereavement Counselling?

Who has a Duty of Care for Providing this - the Fertility Clinic, the NHS or the HFEA?

Introduction and Background

Some years ago I began to work with a new counselling supervisor who had been recommended to me. From having exchanged CVs I knew that she worked as a general counsellor seeing clients with depression and anxiety, very different from my own predominantly fertility oriented practice. Our first meeting took place one evening in her home when we talked for hours about our respective counselling backgrounds and experiences. She was a lovely, gentle but powerful woman and we immediately felt comfortable working together. She had no real knowledge about the role of counselling in the context of infertility management and treatment, so was very interested in my own background in infertility and asked many questions about my counselling approach.

Interestingly it seemed that so many of her clients, both male and female had been through fertility treatments, either with or without a successful outcome, and were now feeling the need for counselling because of this experience, usually but not always because of their ultimate childlessness. As we talked we were amazed to discover that she had, over the years, been seeing and counselling much the same group of clients that I had been seeing in my clinical practice and in the IVF unit. The difference was that she was seeing them some 25 years (a generation!) or so after their original fertility treatment, and primarily because they were continuing to experience the emotional consequences of this treatment. Significantly perhaps this was the time when they might have expected to be going into ‘grandparent mode’ had their treatment resulted in a baby.

That evening my new supervisor was pleased and grateful to learn from me about the journey that her clients had probably been through and felt that this knowledge would help her to understand better some of the problems they were now having, individually or as a couple. However, from my perspective, the significance of our conversation was the realisation, with dismay, how inadequate much of my post-fertility treatment counselling of patients must have been over those years, if her current personal counselling practice experience was the norm. My attempts at helping my clients to manage their fertility-associated loss, my efforts at ego-enhancement, and my talks about there being “more to creativity than procreativity” could very well have been falling far short of truly helping and empowering my fertility patients to move positively forward into exploring other future life plans in a way that did not depend upon their being biology parents.

This feeling was reinforced sometime later when I began working as a primary care medication advisor and running a national helpline for prescription medication dependence. Here yet again I was startled to realise how many of the patients/clients

that I was meeting in the various practices in which I worked were on long term antidepressants, tranquillisers and sleeping tablets as a consequences of their infertility experiences and consequent and often unsuccessful treatments.

What Does Successful Infertility Treatment Mean?

At this point I need to try to define what I mean by success and non-success in the context of fertility treatment, also what these words might mean for patients themselves. Understandably, from the clinic and its staff's point of view, success can only really mean the live delivery of a healthy baby - and certainly this is what is reported back to the Human Fertilisation and Embryology Authority (HFEA), what the Authority then record in their data for the "Patients Guide" and understandably, from prospective patients' point of view, is probably the singularly most important criterion for rating a clinic. However from my own experience of managing a fertility clinic I quickly became aware that things were not quite as straightforward as one might suppose. I was usually seen as the 'Gatekeeper' for the clinic and its Donor Insemination treatment programme, a perception I did not enjoy and immediately dismissed, telling patients that they had their own key to the gate, to use or not as they chose. They were therefore 'in' unless they chose not to be. Obviously there were the occasional exceptions to this where fertility treatment would clearly be inappropriate or even dangerous, medically, emotionally or socially, but these were rare and such applicants would be offered referral to other agencies.

I quickly realised that success for many patients, in the first instance at least, and especially for the older women/couples, could often mean finding a fertility clinic where they felt listened to and could have their views, opinions and feelings respected in a non-patronising way. One where they would be given information to help them to make their own important *choice* about, and then be given the *chance* of, trying for a baby, something that life or other agencies had seemingly taken away. Their initial interview with me was in essence more of a counselling appointment than a booking in for treatment consultation, but it gave such patients the opportunity to talk about treatment options without any commitment to become involved with these. From this first conversation many realised that their chances of success in achieving a baby were so very low, that, with a degree of sadness, they made the decision not to enter into treatment. However they were grateful for the chance to talk about their situation and felt that they now had more clarity about where their future lay.

Some patients, whether single women or couples, whilst acknowledging that there was only a slight chance of their becoming pregnant, felt that they owed it to themselves, their partner and their respective families to at least give treatment a brief, limited try. If this did not lead to a baby then it was meant to be and they felt that they would have done all that was reasonable to have a baby and a family and could then begin to plan the rest of the lives in other directions. Not infrequently potential patients would take away all our literature having booked a medical assessment appointment with our medical director, only to telephone back a few days later to cancel this. As a result of our discussions in the clinic and later their own with their partner or family and friends, they had for the first time been able to admit to themselves that there was no longer a need or a space in their lives for a baby. They just needed the opportunity to talk about

this and know that they were deemed worthy of being accepted for treatment if they chose. Knowing that the choice was theirs, not the clinic's, was the empowerment they needed. Whilst grateful for this chance they now felt able to decide to stop trying for a baby and to explore other routes through their lives. And importantly this was *their* decision, nobody else's.

Sadly 'trying for a baby' can be a very long term activity and the implications of this are not always fully appreciated. I suspect that at times a decision made by a young woman to have a baby in say her 20's but which doesn't then happen, can sometimes turn a genuine need into a *leitmotif,* a desperately recurring theme which persists through her 30's and into her 40's, and which is never reviewed despite her changing circumstances. A decision to have a baby at 20, which would have given her parity and communality with her pregnant peers is a very different baby from the one she tries to have at 35 when her friends' children are approaching university and at 45 when her friends are having their grandchildren. Having a baby and a family is a decision that needs to be reconsidered and remade at intervals and at each milestone rather than being a once and for all plan. From talking with the forgoing groups of patients and seeing things through eyes, I have come to realise that a baby is not necessarily the only, or even at all, the measure of success for many patients consulting a fertility clinic. Whilst these lovely people are still going to have to face their long term need to grieve for their loss, from their feedback to us it would seem that they did nevertheless regard their treatment in and by the clinic as a success for what it had helped them to achieve.

My Personal Theory of Bereavement

Since that initial conversation with my counselling supervisor some years ago, I have experienced my own personal loss through the sudden death of my wife after 53 years of marriage. What I have learnt and am still learning about loss as a result, seems to chime with and has made me see and understand, a little of what many couples and individuals experiencing fertility loss might still be going through as they try to continue their lives in new and none child-orientated directions. What I believe I now know (and wish I had known as strongly 25 years ago) is how much fertility losses, like all bereavements, are complicated by their being of two-fold nature. Just as with the death of a loved relative or friend, there is a double bereavement in infertility that makes the loss of one's self-perceived and assumed fertility and of one's future parenting plans so difficult to deal with and such a long-term project.

What do I mean by a double bereavement? Firstly there is the obvious and immediate bereavement, the physical, corporeal loss of someone or something. Fertility is potentially full of such losses: cycles cancelled due to the failure to respond to ovulation induction; eggs that did not fertilise or the embryos that do not progress normally or implant; the last of one's available embryos failing to achieve a pregnancy; the baby lost during pregnancy; the ending of fertility treatment (no more clinic appointment dates in the diary, letters and paperwork all to be discarded); the end of conversations about pregnancies and parenting; and ultimately, the dashed hopes of a future with children and grandchildren, and of achieving parity with one's fertile peers and other family members.

Some of these have been discussed in detail in a recent article in this journal (Dodd (2021), and are the acute and immediate losses that have to be faced and accepted as and when they arise during treatment. Fortunately, the distress engendered by these seeming full stops will often/usually/hopefully be ameliorated at the time, at least to some degree. This is because they are so obvious to others around the couple or individual, be it their family, their closest friends, fertility support associations, and the clinic staff, doctors, nurses, counsellors, all of whom are available to provide support, to share in the loss, and provide the opportunity to talk. They are part of the ritual accompanying many such losses and rites of passage in our lives.

The second bereavement however is the longer term loss, of the relationship that the bereaved had with their missing loved one, or in fertility contexts, with the attributes of their fertility. For those who are having to come to terms with their ultimate infertility, these are all of the events, memories, conversations, memorabilia pertaining to their 'trying for a baby' that will linger in the mind, body and psyche long after the immediate loss or the cessation of their treatment. But also, as memory works in both directions, these are also all of the future plans, expectations, assumptions that were intrinsic to their planning and trying for a baby and in becoming a parent. These future fertility and parenting milestones will have become implanted over the years long before, and certainly during, fertility treatment, and as such they will be just as powerful and therefore just as painful to deal with and to let go of, as if they had actually happened.

Nevertheless such future losses are all going to have to be confronted in their turn, and be dealt with by the now childless or infertile person or couple, as they move into their new, painfully sad and very different future. For many therefore, the future management of their childlessness will continue to change their lives over the years and as each new milestone comes to pass. This is all part of the 'unfocussed grief' that Diane and Peter Houghton describe so eloquently in their seminal text "Coping with Childlessness" (1987). This process is further complicated for those having infertility treatment as couples, whether heterosexual or same-sex. Where fertility treatment has not been successful in achieving a pregnancy, the patient undergoing the treatment may feel that she has let her partner down by not being able to provide the much wanted baby and family within the relationship. As a consequence she is likely to have a very different subsequent recovery journey from her non-treatment partner, and especially when that partner is male - as I have described in a previous paper in this journal (Entwistle, 2020).

Life Before and After Fertility Treatment

Whilst not all women grow up wanting to have children, most at least feel that this is a possible option for them when the time comes to make such life decisions. Even in today's new multi-gendered world, most women's early childhood still involves role playing 'mums and dads' and rehearsing being pregnant (a cushion pushed up their dress) and of being a mum (nursing, feeding and bathing their dolls). They grow up therefore with the assumption that they will ultimately be able to become mothers, unless they chose not to do so. Although most small boys do not actively roleplay their future fatherhood (except when instructed to do so by their female siblings!), they are nevertheless aware of this as a possible future. Boys do however automatically

assume that they are fertile, and this *certainty* becomes importantly reinforced once they enter puberty, with its dire warnings and awareness of the possibility and risks of an inadvertent and unplanned pregnancy (Entwistle, 2020).Thus both genders have implanted ‘sleepers’ from an early age regarding their future fertility and parenting.

As adults, whilst they still believe themselves to be fertile and future parents (if they so choose), they can take pleasure in their friends’ and relatives’ demonstrated fertility and parentage, attend family christenings and children’s birthday parties, and feel comfortable during discussions with their peers about child-related activities such as nurseries, baby clothes, schools etc. This, whether they have already begun to actively try for a baby, or whether they are still at a more-long term ‘planning their life together’ stage. But once they ‘lose’ their fertility and with this, the likelihood of experiencing pregnancy, childbirth and of being parents, then their whole world is destabilised and the impact of this is felt in their relationship with themselves every bit as much as with their partners. Even though as a couple they will both be feeling the loss of a future as parents, they nevertheless will now have each begun their own unique journey through their childless future. Unfortunately however this future will inevitably be made more distressing by the unwanted, repeated and painfully intrusive occurrences of fertility related events, episodes and discussions which will prove impossible to avoid throughout their continuing lives

What makes coping with this life changing process further problematic is that relationships, of any sort, are built up through shared hopes, plans, experiences and events. These are the links and the rungs that bind us to one another and equally importantly which give cohesion and structure to our various inner selves, helping us to shade and justify our lived experiences both individually and with others, including our partners. For fertility couples and individuals, with the ending of fertility treatment and of all expectations of pregnancies and children, these previously shared fertility and parenting contexts and experiences are no longer valid or relevant within their relationship with their partner nor within themselves. What were once ties that acted positively to bind their relationships with their partner, may become more painful and contentious memories which act to push them away from their partners and from family and friends, and undermining what they feel about themselves. This is especially so for those whose choice of a partner was predicated on their future parenting together, as is often the case. During this new and unexpected future many will therefore begin to experience the negative emotions such as anger, shame, guilt, despair and hopelessness that are frequent concomitants of having to accept a future life very different from their seemingly pre-ordained life path.

Fertility Bereavement Counselling – Whose Responsibility?

Within the context of fertility assessment, and IVF and allied treatments, counselling seemingly has a clear if limited, and not least, HFEA defined, role and function. Primarily this is to ensure that patients understand the implications of their fertility investigations and treatments so as to be able to give their informed consent or dissent to participating in the fertility clinics activities. Presumable support and a shoulder to cry on are included in this function. Reading through the HFEA website however there seems little positive guidance or even reassurance about what fertility counselling

really means and encompasses, and nor about its easy and free availability within the clinic for potential or actual patients. Although there is some brief reference to helping patients to cope with unsuccessful cycles and treatment, there is little to suggest that HFEA licensed clinics have any obligation or remit to provide longer-term counselling for those patients ultimately unsuccessful in achieving their much wanted baby..

If there is a demonstrable need for extended counselling for couples and individual patients after cessation of their treatment, especially for but not necessarily limited to, those who have been unsuccessful in achieving a baby, then whose responsibility should it be to provide this? The choice of options for this seems to include the current range of IVF clinics both private and NHS based, the HFEA, the NHS generally including primary care practices, charitable and other agencies such as BICA, or that it be left for ex-patients to seek out longer term counselling through individual private counsellors.

Looking first at the private, commercial IVF clinics. These clinics are highly profitable businesses which benefit from a seemingly inexhaustible demand. However the fees charged by these clinics for their services and treatments are very substantial for the average individual or couple, even though these may be appropriate for the amount of time and input that is required and the wide range of staff necessary to provide the service. In this regard however the HFEA has recently expressed some concerns about the increasing use of expensive ‘add-ons’ which are often of limited value or efficacy. I have no personal issues against private medicine having run a private clinic myself for a while and had a private counselling service for many years. My reason for suggesting that private IVF clinics should consider providing more follow-up counselling for its patients, either for free or for a nominal charge, is simply that such clinics, in part at least, are responsible for generating the increasing long-term stress and consequent counselling needs of patients with infertility problems.

Many couples will have had to go into debt or sacrifice luxuries and holidays in order to fund their fertility treatment privately. But despite this, for three-quarters of these patients there will be no resulting ‘happy ending baby’. This is in sharp contrast to the usual success rates of around 90-100% for most other self-funded private medical treatments such as hernia repair, cataract removal or haemorrhoid treatment. Unfortunately, the nature of human fertility means that success rates for fertility treatment will always be disappointing low, a depressing picture which sadly cannot be remedied. Although patients will have been told that the likelihood of a successful outcome is of this low order, desperate patients will often refuse to hear this. The ultimate failure of their perhaps ill-afforded treatment will therefore come as an unexpected and bitter disappointment, and the consequent emotional sequela will add to the stress of their treatment regime and possibly engender long term distress and a counselling need during their long recovering future.

I also have concerns that the increasing visibility of the tempting shop windows displayed by private fertility clinics during fertility and patient support conferences, in the media and on the internet, with their portrayals of smiling, often older mums, with ‘babies they’ve prepared earlier’, could be seen as creating a new and inappropriate demand for the clinic’s services rather than simply answering an existing one. Such

high profile advertising approaches, by raising the hopes of women and couples who may have started to come to terms with living a childfree life, could be opening old wounds unnecessarily and futilely and be generating further distress and a future counselling requirement. For each 100 woman that these adverts persuade into treatment, 75 women will ultimately be unsuccessful in producing a child and may require counselling for this in the future (HFEA 2021).

Fertility clinics run within the NHS will also generate similar long-term post-treatment distress, less because of patient self-funding issues and more because of issues around waiting times, appointment times, limitations on the number of cycles, prior children, and the patients' ages. These will all put pressure on patients using NHS clinics, which can overflow into long term dissatisfaction and distress necessitating future counselling. Not all of this can justifiable be passed back to other areas of the NHS psychological services or to hard pressed general practice counselling facilities. Interestingly the NHS website recommendations for obtaining counselling help and support in managing IVF and allied stress is to refer patients to the HFEA website, whilst the HFEA website in turn recommends that patients should consult the NHS for such counselling information and support –a neat trick?

The HFEA have mandated the availability of counselling within licenced clinics and review this provision as part of the regular inspections. However even their own website suggests that counselling may only be available as an extra and for a fee, and that perhaps patients should consult their GP or pay privately. Some 15 years ago as an exercise I telephoned fifty of the UK fertility clinics asking to speak to their counsellor, purporting to be a patient. The most frequent response was either a stunned silence followed by a whispered discussion at the other end of the call as the clerk, nurse or medic asked a colleague whether they had a counsellor in the unit. Alternatively I would be told that there was a lady who came in from 'time to time' to talk to patients, but that she only came in occasionally if asked to and that there was a waiting list for this. Sometimes it was kindly suggested that I should call Samaritans or my GP if I was feeling in need of counselling.

I would hope that since that time the picture has changed and that the counsellor is now seen as an intrinsic member of the team, and fully accessible counselling as a normal part of the clinic's activities. However to extend this into an efficient extended follow-up or 'after care' counselling service for a clinic's ex-patient workload, whether private or NHS would clearly be a major commitment for the average clinic counsellor, and this would also clearly need to be based off-site of the clinics' treatment facilities.

An alternative approach would be for the HFEA to take over this post-treatment counselling role, just as it has seen fit to initiate a free counselling service for certain other ex-users of fertility clinics, i.e. donors and donor conceived children and their families. Hopefully this will one day be extended to help other post-fertility patients and their partners. Finally there are the fertility and counselling support agencies such as Fertility Network UK, Fertility Friends, Miscarriage Association, the Ectopic Pregnancy Trust, Ectopic Pregnancy Foundation, Multiple Births Association, several on-line support lines, and most especially BICA. All of these offer free advice, and some limited free counselling.

Of these only BICA and its membership could be seen as fully qualified to offer an appropriate and comprehensive fertility counselling and advice service, although the cost of private counselling could still prove prohibitive for many childless couples over the long term necessary for them to resolve their distress. Perhaps therefore it is time for there to be a *fertile* liaison between BICA, BACP, these other agencies, and counsellors in general, one in which staff and counsellors could receive some appropriate training and support from BICA for a moderate fee, in return for which they would refer more complicated counselling needs clients to BICA members perhaps at a reduced counselling rate?

Over the past two decades there seems to have been an ever increasing focus on and awareness of infertility. No longer does it need to be kept a secret it seems but is now an acceptable fact of life and a suitable case for treatment. Unfortunately however, advances and research in fertility are also increasingly giving the impression that the new assisted reproductive technologies can provide everyone with a chance of having their baby. As a result fertility clinics (unwittingly perhaps) are contributing to the ever growing multitude of infertility bereaved people whose hopes have been raised by advances in fertility treatment only to be quashed by the inherent limitations, inevitably low success rate and relative unaffordability of such techniques. The sad truth is that these treatments which might make having a baby more of a possibility are still more likely still to generate a new fertility bereavement.

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