Counselling, care in infertility: The ethic of care

T Appleton
Bourn Hall Clinic, Bourn, Cambridge

Infertility is a health-care problem which has very definite physiological, psychological and social implications. Infertile couples are continually reminded of their plight—the structure of society is based on the family unit; simple activities such as shopping are a constant reminder, the shops being geared to the family; the neighbours fill their cars with all the paraphernalia which accompanies children—the stigma of infertility often leads to mental disharmony, marital difficulties, divorce, and in some cultures to ostracism. The suffering experienced by infertile people is very real.

We need to remind ourselves that we are treating 'people who are infertile' rather than 'infertility'. Our care goes beyond their physical treatment—their stresses and strains are our concern and we must be careful not to add additional stress to their existing problems.

Successful treatment can transform their lives: 'They are bright, healthy, beautiful children—a dream come true. Our lives are transformed and complete. Thank you a million times.'

Failure after years of trying is all the more painful. The availability of effective, informed, independent and involved counselling is essential.

'Counselling is a key element in the provision of any infertility service ... Counselling should be distinct from discussions with a doctor of any medical treatment he proposes and should be carried out by somebody different, preferably by a qualified counsellor' according to the Government White Paper, Human Fertilization
The Warnock Report emphasized the need for counselling services: 'We recommend that counselling should be available to all infertile couples and third parties at any stage of the treatment, both as an integral part of the National Health Service provision and in the private sector. We recognize that there may not be sufficient counsellors trained in this field at present, but we feel it is possible for counsellors trained in other fields to adapt their skills to deal with infertility.'

'Counselling ... does not ignore the obvious, but seeks to reach behind it. It requires the giving of sufficient time to help a person in distress to uncover and reach some of the less obvious and less acceptable feelings and thoughts which contribute to unhappiness and dissatisfaction. It is an approach which has isolated certain factors in caring relationships and stressed them, while at the same time played down other factors such as giving answers, expressing sympathy, or actively trying to change the circumstances which appear to contribute to the distress ... it is above all an approach which tries to understand what goes on inside people, and how internal difficulties can stand in the way of change, rather than looking at external factors or external solutions.'

The term 'counselling' is used in many different contexts. In this chapter I try to identify different kinds of 'special patient needs', to separate the approach of counselling from other aspects of patient care.

The 'ethic of care' is particularly important in the care of the infertile. Nurses and 'nurse-coordinators' play a vital role in many aspects of this care. But we need to distinguish between providing 'information, support and care' from that of counselling. Counselling should involve those with experience in counselling. Patients can become confused when two roles and mixed—e.g. nursing and counselling, clinical consultation and counselling. The first three categories can be covered by nurse coordinators, nurses and other staff under the guidance of counsellors. The remaining categories need the help of those with counselling skills.

SPECIAL PATIENT NEEDS

The options available

This involves helping couples to understand the various options open to them—medical intervention, adoption, coming to terms with childlessness—and realizing that they will inevitably face
considerable stress with the probability of disappointment during their treatment. Failure is still more likely than success and this can be hard to bear.

**Understanding infertility**

Patients who present themselves for treatment are often very ignorant about the processes of reproduction and their vision of treatment is clouded by fear and embarrassment. A vital component of patient care involves education which may take the form of illustrated talks, provision of good booklets, the use of 'in house' video-films which can be regularly updated, and carefully prepared poster displays.

**Support**

Support at such times will be sought from nurses, doctors, nurse-coordinators, fellow patients and specialist counsellors. Support must be both informed up-to-date and above all realistic. Those providing support must be able to realize their own limitations and be ready to refer patients to others with greater clinical, scientific or counselling experience where the need arises.

**INFORMED COUNSELLING**

Counselling is more effective if those concerned have the trust and support of both staff and patients. Counsellors must be prepared to keep themselves informed about new developments, to make their contribution towards the development of new protocols, and to have the humility to know when help from someone of better qualified is needed. The essence of good counselling is to enable those seeking help to make their own decisions, to 'meet them where they are and not where we think they ought to be'. Although they are still our concern, some of their pressures and anxieties may be unrelated to their actual treatment. This inevitably means that we have to be prepared to listen more effectively, and provide the right environment and the time which is needed.

**The use of ‘donated material’**

Treatment which may suggest donor gametes, embryos or surrogation will need particular attention and care. All couples for
whom donor gametes may be necessary must receive independent
counselling. Counsellors will need time to explore the implications
for the couple, the future of the family, the fact that the child is of a
different genetic origin to either or both parties, the ethnic or
religious background and the legal situation. Sufficient time and
space must be allowed to enable all parties to face the realities of
donation. Patients will need help in understanding the nature of
confidentiality ... should they tell other members of their families
... should they, or must they, tell the child the nature of its
conception ... will the law require them to tell the child ... secrets
are difficult to hold and the child might find out indirectly, more as
a result of what is not said rather than what is. Should donors be
anonymous ... or is it acceptable that brother can donate to
brother, sister to sister, or friend to friend.

The current guideline\(^5\) from the Voluntary Licensing Authority
(VLA) suggests that in the case of egg donation known donors
should be avoided, i.e. that anonymity should be maintained. A
recent meeting organized jointly by the King’s Fund Centre and
the VLA in September 1988—where representatives from clinics,
patients and counsellors listened to arguments presented by
anthropologists, psychotherapists, lawyers and sociologists—re-
commended a flexible approach with effective counselling and
with the guidance of local ethical committees. Parallel arguments
from the experience within adoption suggested a cautious ap-
proach. Who should decide? Does the donor have a point of view?
Are the patients’ wishes paramount? Does a child have the right to
 know ‘its’ genetic origins? Does the availability of donors have an
impact on decision making? How can we best support our patients
in the long term without intruding upon their privacy? Counsell-
ors must be satisfied that all are equally confident in their
acceptance of the use of donor material before treatment with
donated ‘material’ is approved. However, it is not the role of the
counsellor to make decisions for others. Our task is to provide the
time, the environment and the opportunity for couples to under-
stand the facts, to consider the options available, to recognize their
own deep-rooted feelings, and to equip them with an appreciation
of the implications for them as a couple and as a future family.

Availability

Clearly not all patients need ‘in depth’ counselling but they should
be aware that counselling is available and to know how to make
contact when the need arises.
AREAS FOR SPECIAL ATTENTION

In my experience, approximately 44% of our patients bring with them symptoms of stress. Counsellors should also be aware that the staff themselves may need support and help. Among those areas where special attention may be needed are:

*Emotional*

Patients frequently show signs of stress or may be in a highly emotional state for reasons which may be unconnected with their treatment. Such stress can often make their treatment almost unbearable. Marital, family, cultural, religious, financial and social pressures can add to the stress of infertility.

*Guilt*

Many patients have expressed feelings of guilt, anger and shame after failures in stimulation, fertilization and implantation—Why did it happen?—Why am I being punished?—It is because of something I did in the past? ... because I was ill? ... because I was promiscuous in my youth? had an abortion? Feelings of guilt may have been imposed upon them (consciously or subliminally) by the attitudes of religious leaders or the press. The sense of failure can intrude upon the rest of their lives—they are constantly reminded of that failure. Our help as counsellors goes beyond the immediate treatment cycle. Outreach is essential.

*Grief*

Patients need time for grieving. There is a very real sense of bereavement when a pregnancy goes wrong—following ectopic pregnancy, miscarriage and still birth. A patient who has experienced both success and failure in a IVF clinic said: 'The sorrow of infertility for a happy couple can be compared with the sorrow of bereavement. The funeral starts when a couple learns the results of tests and continues with surges of hope that a miracle might happen. Sorrow is private, real and often taboo; failure at any point is always very painful.'

Grief hits people in different ways. In grieving, people need to lick over their wounds but also need to be surrounded by love and support. The trouble is that grief often comes on top of other
troubles and at times when we least expect it. The process of recovery involves a need to change from a negative attitude into a positive one. Often no easy matter.

**Marital and sexual anxieties**

Infertility treatment imposes considerable burdens on the marriage/partnership. One partner may have a stronger need to continue the quest and, at times, this may become an obsession which ruins the rest of their lives. Some couples have not given themselves the opportunity to face up to the situation or have consciously or subconsciously avoided asking the obvious questions of themselves or of their partner. They have sacrificed their holidays to pay for the treatment; they need help to decide for themselves when they should stop; they need help in coming to terms with the fact that treatment is not going to be successful and that there are other aspects of their life which are suffering as a result. They may need help to enable their relationship together to flourish again.

**Abnormalities—mild and severe**

Although it is becoming clear that the incidence of abnormalities among children conceived as a result of the new reproductive technologies is no higher than in the general population, the ‘disaster’, when it occurs, is potentiated by the fact that some ‘intervention’ has been necessary in the first place. Were the abnormalities caused by the treatment? Is this my punishment? Was it the fault of the donor sperm used? How can I bear to face the future? If only I had known earlier. I might have terminated the pregnancy. These and many other questions will inevitably be asked or, worse still, suppressed. If we ourselves cannot provide long-term counselling and specialist care we should know who to refer patients to, and put them into contact with the local specialized support groups.

**Frozen embryos?**

Freezing and storage is becoming part of the treatment in many clinics; but for some couples it raises further stresses. What are the options available if patients have frozen embryos in storage and no longer want them? Can we donate them to another couple or to a
single woman? Should we allow them to be used for research or just allow them to die? Who decides? What happens in the event of the death of one or both partners? Can the surviving partner have the embryos? When frozen embryos are in storage and the storage interval has elapsed, how do we approach the surviving partner? For some patients, these questions cause problems in accepting the idea of freezing and storage. We may take it for granted that they will want freezing but this may not always be so. The programme for replacing frozen-thawed embryos itself is often very stressful. Many have said that a full cycle of treatment is much easier, for there are at least hurdles along the way which mark their progress, but with FeR no news is really available to them until the day of replacement.

**Long-term support**

We can easily understand why couples need support and counselling when things go wrong; we do not as easily recognize that when treatment is successful, support of a different nature may be needed. Couples who have been infertile for many years do sometimes find it difficult to come to terms with the fact that they are now a family—not just a couple. A patient who had been successful wrote this comment on the bottom of a follow-up questionnaire from the MRC:

'I do feel that more counselling ought to be available to patients contemplating IVF. This should follow through to help overcome the problems faced when failure or success results. There are associations to help people overcome the problems of childlessness but not a lot is offered to overcome problems experienced when IVF is a success. After years of infertility it is very difficult to accept that one has a child and to come to terms with caring for it. One tends to think that one is still living in fantasyland not reality.'

The investment in terms of stress, time, money, etc may have been very great and some have expressed the need for counselling as the child grows. At least one couple has estimated that their child cost at least £16 000, and a sense of 'over-investment' may arise as the child grows through 'problem' phases. Our ultimate responsibility is not just to the couple suffering from infertility but to the family which hopefully arises from medical assistance.
REFERENCES


3 Hugh Henderson. From a letter to the Daily Telegraph, 6 June, 1985


5 E.B.—a patient from Bourn Hall Clinic

6 M.P.—a patient from Bourn Hall Clinic