

## ***AT ISSUE*** **THE POLITICS OF INFERTILITY “COUNSELLING”**

JOCELYNNE A. SCUTT

Barrister-at-Law, Owen Dixon Chambers, 205 William Street, Melbourne, Victoria 3000, Australia

The 20th century has seen the introduction – at least among those who fall into the economically affluent category – of what is now a burgeoning field (some might say “industry”). That is, counselling. Counselling is regarded by some as a boon to all at one time or another, in one circumstance or another, and the saviour of many. Counselling is even required in certain situations. In Australia, the Family Law Act legislatively dictates that women and men undergoing marital breakdown, particularly where problems of custody and access arise, must undergo counselling before they can obtain a court hearing. In some states, legislation dealing with artificial reproduction – in vitro fertilisation (IVF) gamete intrafallopian transfer (GIFT), and other new reproductive technologies – provides that counselling must occur before a “couple” is accepted on to a programme.

Some may believe that counselling is a “good idea” where the “option” to undergo medically and socially intrusive treatment and operations is available. Others may take the view that counselling is essential if the “right” people are to be selected on to new reproductive technology programmes. Yet even these two differing positions reveal a problem that is inherent in the very notion of counselling: People have very different views of what the aim of counselling should be, and of its desired outcome. And some of these people are the counsellors.

Others consider that any counselling is in itself intrusive; that it is a means of “putting people through the hoops;” that it is programmed to bring about a certain outcome, so that people going through counselling learn what they should and shouldn’t say, how they should and shouldn’t act. Thus, counselling has a self-fulfilling purpose.

The experiences of women who are classified “infertile” may initially give rise to the notion that counselling is a good thing, and that counselling programmes have been introduced because women need them. Yet this is questionable.

In 1983, Naomi Pfeffer and Anne Woollett published their book, *The Experience of Infertility*. Each had previously found she was unable to conceive a child and had sought help from their respective medical practitioners. Each went through infertility investigations. The causes of infertility differed, but their experience of the investigations was similar: a sense of isolation, “the feeling that we alone were having this experience.” They sum up the reasons they found were shoring up this isolation:

It stems from a lack of discussion generally about infertility, surprisingly so, as . . . many women face this problem and experience [similar] feelings. . . . It stems from the books . . . on infertility, most of which are written by doctors and from the doctor’s point of view. Although many of them spell out the physical aspects of infertility and describe the investigations, none of them describes what it is like from the woman’s point of view. (Pfeffer & Woollett, 1983, p. 1)

Naomi Pfeffer and Anne Woollett found “lots of information about the mechanics of the tests,” but no understanding of the feelings women experience in undergoing them, whether they cause emotional upset, or whether they simply “hurt” physically. Because they felt no sense of connection with the books written by the medical profession, the women experienced feelings of being

bizarre or unusual. Even with the Women's Movement, it was difficult to discuss infertility and the anxieties and stresses, the possible comforts and solutions, they experienced as "infertile women."

This highlights the inadequacies of "infertility counselling" today. Just as Naomi Pfeffer and Anne Woollett found that, in the United Kingdom, infertility was regarded from a particular perspective by professionals and in the written word, other women have found similar problems in Australia, countries of the Asia-Pacific Region, South America, North America, Europe, and elsewhere. Infertility is seen as a defect to be overcome; as an illness; as a medical condition requiring correction through medical means. There is little or no conception, in conventional circles, that infertility is not a "disease" to be corrected by medical treatment or its traditional equivalents. This failure of vision extends into the field of counselling.

### INFERTILITY COUNSELLING

Known and publicised infertility counselling programmes are connected with new reproductive technologies, including IVF and GIFT. There is no independent counselling. Rather, women who are already "on" new reproductive technology programmes, or who have made a decision to adopt this as a (hopeful although mostly hopeless) solution, have access to counsellors whose jobs are created by the hospitals or clinics running the programmes. A woman experiencing difficulty in conceiving does not have access to counselling directed at her (or her husband or partner's) perceived condition; rather, the counselling is directed toward a particular "solution" to the "problem."

Even here, the dice are loaded. There is one "solution": new reproductive technology. Counselling (where it is available) is programmed into the provision of these technologies, rather than being provided without any directives

as to the outcome of counselling.

If a person suffers from a particular health condition, the treatment she or he receives is heavily dependent on the health professional she or he approaches for help and advice. Those who approach a specialist in alternative medicine will not be presented with a choice of radical surgery. Those attending a traditional medical practitioner will not be presented with a choice of nontraditional treatment. Those attending an IVF clinic will not be presented with a choice of alternatives to new reproductive technologies. The assumption is that the person has made the choice before attending the particular professional or specialist.

Pat Brown, a child psychologist working in Melbourne, Australia, has written of the misgivings women have in being "counselled" on IVF programmes (Brown, 1985). These misgivings have been expressed by others writing in the field, and who have (in their own words) chosen new reproductive technology as a means of overcoming infertility. The reservations include fear that counselling is designed to eliminate those who do not "fit in" to the appropriate model from new reproductive technology programmes. Prospective IVF participants are reported as discussing the appropriate clothing to wear to counselling, and the appropriate demeanour to adopt. Counselling is seen as a necessary hurdle to overcome in "passing," and being permitted to remain on a programme.

A participant in an Australian programme reports:

When we finally [after eight months] heard from the IVF clinic, we were asked to see an IVF counsellor first. With hardly any warming-up time he asked us if we had a good sex life and whether our marriage was happy. Of course we both nodded – obviously convincingly because he made a note somewhere on his form and then declared that we seemed emotionally stable and therefore were accepted on

the programme! My husband and I both laughed about it afterwards. What a joke – who in their right mind after waiting so long would have even breathed a whisper of any difficulties? (Klein, 1989, p. 20)

Another writes:

In retrospect I realised it was a big mistake not to see a therapist before beginning IVF. I wasn't at all sure whether I had the energy to try again – and to cope again with disappointment. But I felt everyone was pushing me into it . . . gently but steadily. . . my husband, my mother, my best friend, even a girl at work whom I had told about it. I felt really caught. . . . When we went to the initial counselling there was no space to say any of this. We were given the impression that it was a big privilege to be accepted – and we were – so we had to be grateful. I shut up and began three years of utter misery. (Klein, 1989, p. 20)

The director of one Western Australian programme was widely reported in the media as conceding that there were problems of people being unhappy on the programmes and not being properly informed about the experience prior to participating. His solution: incorporate counselling into the programme (Yovich, 1990). There was no recognition that for counselling to be effective, there must be multiple choices presented to those attending. Counselling should not be projected simply as a preliminary to becoming an active IVF participant. This presupposes the outcome: it is IVF, or nothing. In these circumstances, it is little wonder that many women (or couples) accept the notion that IVF and other reproductive technologies are a solution to infertility. They are not presented with any other possibilities, any other ways of regarding infertility, any other ways of dealing with infertility in its social and political perspective.

Commenting on counselling in the context of such programmes, the biologist and researcher Renate Klein writes:

Counselling . . . at this stage, and under these circumstances, has to be seen as tokenism. Conversely, there seems to be a real need for independent counselling which might help people with an infertility problem to put a halt to the “insemination circus” as one woman called it, feeling both sarcastic and desperate but still agonising whether to try IVF for the third time. If such counselling were available and easily accessible, *some* women might decide *not* to embark on IVF. (1989, pp. 21-22)

Rather than being infertility counselling, this is IVF or new reproductive technology counselling. Yet the tragedy is that it is the most widely available counselling for those who experience infertility as a disability, a problem to be overcome, or come to terms with. Yet even regarding it in this light, limitations are recognised and criticism expressed by those participating:

With hindsight I feel that the limited amount and content of the counselling that we received was fairly useless. It did little to prepare you for the actual physical and emotional demands placed upon you while going through the programme. (Klein, 1989, p. 23)

#### **LIMITATIONS OF CURRENT INFERTILITY COUNSELLING**

Medical practitioners working in infertility express concerns about the limitations of counselling. This concern is based in the narrow perspective of those who are medically trained, and the narrow confines of solutions projected through the medical model. John F. Kerin of the Department of Obstetrics and Gynaecology at the University of Adelaide writes:

As the options of treatments improve in order to cope with the more complex infertility problems, women will have to make increasingly more difficult decisions with respect of the wisdom of undertaking or declining such treatment while all the time the elusive desire for pregnancy continues. This is compounded by the fact that women are still strongly conditioned to having a child or children of their own in our society. They are subject to potent pressures from their partner, peers, parents neighbours and friends. The biological-social drive of many childless women to have children is acutely felt by the medical personnel involved in fertility management and it often becomes very difficult to decide just how far to take many couples along the long path of fertility management. (1985, p. 8)

He continues:

In order to arrive at a wise decision, it has become increasingly necessary for the medical team to widen their counselling base by engaging the resources of people who have the necessary time, sensitivity, counselling skills and a good deal of common sense to help couples work through their infertility problem and reach the decision which is correct for them. The basic ongoing decision is usually to embark upon further treatment, consider adoption or accept a lifestyle of child-free living, (p. 8)

Kerin expresses concern not only about those professionally engaged in medicine, but about the peer group and social pressures operating on those who are classed as infertile. He notes there are "ethical and judgmental pressures" transferred to infertile couples by community groups. These pressures are intensified, he observes, when "added to the stresses already being experienced by couples on such programmes."

Pressure can be expressed in a constant reference to a woman (or couple's) childlessness, with questions such as "when will you start a family?" Or it can come in the form of pointed avoidance of the childlessness of the woman (or couple). Naomi Pfeffer and Anne Woollett describe instances of this occurring. They quote one woman as saying:

When we were first married, I happened to be known to be very fond of children. It was just assumed that I would want a baby. So people found it very easy to talk about it for the first year. Now they've stopped. (Pfeffer & Woollett, 1983, p. 34)

They go on to relate the difficulties confronted when a woman's parents experience her infertility as a loss to them meaning no or fewer grandchildren. The parents may well have sympathy and concern for their daughter (or son), but also "have cause for grief themselves":

My family haven't really wanted to talk about it. I think it brings them a lot of pain. They don't know how to talk about it. Presumably they don't want to upset me. They know we've tried for years. My father-in-law said he would like a granddaughter, he's got three grandsons. That was just a slip. (Pfeffer & Woollett, 1983, p. 35)

Grief and feelings of failure; pressures from family, friends, workmates and other peer group members; and limitations of medical practitioners and other professionals working in fields that treat infertility as a medical problem to be overcome by technology are not addressed in current infertility counselling programmes. At least, they are not confronted in counselling programmes now being made available to those who define themselves infertile by registering with an IVF programme.

## REORIENTATING INFERTILITY COUNSELLING

In her book *Whose Body is It – The Troubling Issue of Informed Consent*, Carolyn Faulder (1985) sets out five principles that necessarily underpin any programme designed to ensure those consenting to medical treatment do so from a fully informed position. They are:

- autonomy  
 Deeply embedded in the principle of autonomy is the concept of “respect for persons”, and one of the ways of expressing that respect is always to assume that they wish to exercise their rights unless they indicate otherwise. In the medical context, that respect between persons for persons is expressed by doctors *enabling* patients to give their informed consent . . . [O]ffering them the opportunity to be informed as much . . . as they require. To do less than that is to deny them their autonomy, (p. 23)
- veracity  
 . . . trust . . . can only be based on accepting this principle. . . . Doctors expect their patients to trust them to act always in their best interests, to prescribe only treatments which they consider to be beneficial and to place their skills and their experience at the disposal of their patients, (p. 25)  
  
 But trust without truth from the party who is trusted is empty of meaning.
- justice  
 . . . [this] acknowledges the claim for patient autonomy by enabling it to be exercised, (p. 27)
- beneficence  
 [This is] the duty to do good. In the negative sense this is interpreted as preventing harm; in the positive sense it means producing benefits of some kind. (p. 28)

But it can never be forgotten that the question of who is to decide what are the best interests of the patient cannot always be answered (or even mostly be answered) by the words “the doctor.”

- nonmaleficence  
 . . . a positive principle not to do harm as opposed to merely preventing harm. (p. 30)

These are principles that may readily provide a base for infertility counseling – if counseling is an answer, or part of the answer. But it is vital that such counselling be introduced outside the medical context. One of the overwhelming difficulties is that the classification “infertile” is considered a medical problem. Once infertility is defined in this way, limitations inexorably enter into the design of any programme to address it. Rather, counselling should come before the medical definition has been imposed on the condition or, rather, on the person (Solomon, 1988).

Around the world, women have begun to come together in a recognition that existing avenues available to those who are childless but do not want to be, current counselling, and contemporary treatments, are inadequate and, rather than assisting, compound the problem or indeed create it. In West Germany, Ute Winkler and Traute Schonenberg write of a counselling programme – arising through discussion between and among women seeking support – that takes as its basic principle the fact that infertility and involuntary childlessness need not be identical. As one woman put it:

Infertility and childlessness are two different things. Suffering caused by infertility is not necessarily the yearning for a child . . . Infertility is also the loss of biological potency. This fact is often denied – especially by doctors. They make women believe that all that needs to be done is the curing of the symptom, as if involuntary childlessness could be

equated with disease. In doing this they implicitly reduce women to the socially accepted image of mothers: the loss of potency gets defined as a loss of Self. As a consequence the woman's integrity as a person in her own right is violated. (Winkler & Schonenberg, 1989, p. 209)

In the West German programme, there is a refusal to emphasise involuntary childlessness. The whole woman is placed as a complete person at the centre of the discussions. This enables the involuntarily childless woman "to confront her problem outside a medical context." The aim is to have the women themselves seek out, or initiate, the "counselling": This may be through formation of a self-help group or contact with other women and an exchange of experiences. Psychological counselling and/or therapy may be an outcome, but it is not the only outcome, nor a directed outcome. Nor is medical treatment an outcome.

In Australia, Lindsey Napier established Concern, a very small self-help group. She found, however, that although the women were able to give one another strong support, the limitations set by lack of funding and inadequate hours in the day meant it was difficult to keep the group afloat. She writes:

. . . we do not take money from anyone, then you're not beholden to them. But the danger is that such groups become a place where people come in and get support to go straight into medical technologies! What I had wanted was to create a place where people – women – can come and be angry, and grieve and do all that is necessary to find ways of moving through infertility. But the pressures of the technologies, specifically IVF, are hard to keep at bay. Beside the support needs are monumental. All the self-help groups provide a voluntary unpaid service – everyone is doing it at nights, on the weekend, many going through

the mill themselves. The pressures to *give* people things to take away the pain are enormous; there is just no place for them to spend days working through a tiny little bit. I could afford good therapy twice a week for three years, other people can't get that. Women have so much to offer one another . . . but the problem is, the resources aren't there to do it. I am very concerned about that. In the meantime, reproductive technologies get advertised loudly. And women often only come to us after they've already been through years of medical treatments and are at the end of the line – the same moment when social workers are often called in. It's very difficult, in the face of so much despair, to stay away from technology at all. I was shocked when I heard myself saying, "What kind of medication have you been on?" "What kind of medical help have you received?" "Do you plan to embark on another programme?" because I didn't have anything else equally powerful to offer. (Napier, 1989, p. 194)

Lindsey Napier concludes: "Medicine and technology are extremely powerful and we need equally powerful alternatives so that people feel they have a real choice" (1989, p. 194).

Until counselling for infertility is provided as an independent service disassociated from medical solutions to infertility, it will continue to create a self-fulfilling prophecy: Those who attend counselling attached to IVF programmes will inevitably "choose" IVF. If they are eliminated from the programme after counselling, they will inevitably see the failure as theirs: They did not perform suitably through counselling. Counselling that is seen as surmounting the hurdles, or a necessary adjunct to the inevitable medical programme, is not counselling for infertility. Rather, it is counselling *onto* or *into* a particular mode of treatment.

The 1970s and 1980s saw an increasing emphasis on the need for those who are disadvantaged, discriminated against, or classified in special categories to join together to determine their own needs and to find their own directions. There was a complementary recognition that those groups ought not to be expected to “do it all themselves” in the sense of raising all their own funding, creating their own support without assistance. Rather, there was a growing notion of the responsibility of the broader society to support diverse groups through community funding and the provision of other resources in recognition of the fact that each person has a right to determine the parameters, but we as a society have a responsibility to provide the resources for them to do so, and to work toward the achievement of these goals.

For those who experience infertility as sorrow and loss, it is essential that they be able to create counselling initiatives between and among themselves. It is futile to provide counselling within a framework that presupposes an inevitable outcome. Infertility counselling to date has developed in the context of medical technologies. It is important that it be given the resources to develop outside that context, so that the infertile may themselves determine their direction, in circumstances wherein the notion of choice becomes more real. Counselling for a technological solution does nothing to confront infertility as a notion, nor as a real condition of distress.

### ENDNOTE

This article is a revised and extended version of a paper titled “Infertility Counselling: A Critique” presented to the St. Vincent’s Bioethics Centre Conference, Melbourne, Victoria, Australia in May 1990.

### REFERENCES

- Brown, Pat. (1985, May). *IVF – The “simple case”*. Paper presented to the Liberation or Loss Conference, Canberra Centre for Continuing Education, Australian National University, Canberra, ACT Australia.
- Faulder, Carolyn. (1985). *Whose body is it? The troubling issue of informed consent*. London: Virago.
- Kerin, John F. (1985). Conflicts associated with advances in reproductive technology for women. In E. Kerby-Eaton & J. Davies (Eds.), *Women’s health in a changing society* (Vol. 3; pp. 7–8). Adelaide, South Australia: Second National Health Conference, Office of the Women’s Advisor.
- Klein, Renate. (1989). *The exploitation of a desire. Women’s experiences with In Vitro Fertilisation: An exploratory survey*. Geelong, Victoria: Deakin University Press.
- Napier, Lindsey. (1989). The barren desert flourishes in many ways: From infertility to in-fertility. In Renate Klein (Ed.), *Infertility: Women speak out about their experiences of reproductive medicine*. London: Pandora Press.
- Pfeffer, Naomi, & Woollett, Anne. (1983). *The experience of infertility*. London: Virago.
- Solomon, Alison. (1988). Integrating infertility crisis counseling into feminist practice. *Reproductive and Genetic Engineering, 1*, 41–49.
- Winkler, Ute, & Schonenberg, Traute. (1989). Options for involuntarily childless women. In Renate Klein (Ed.), *Infertility: Women speak out about their experiences of reproductive medicine*. London: Pandora Press.
- Yovich, John. (1990). *The West Australian*.