

IVF AND CANCER: A PERSONAL EXPERIENCE

MARCIA O'KEEFE

2/18 Davisons Place, Melbourne, Victoria 3000, Australia

INFERTILITY AND IVF

When Alexander was about three John and I decided that we would try for another child. This time, at least, we would be going into it with our eyes open and without romantic ideas about having the sort of baby other people have (i.e., one who eats and sleeps when you think he should). We also felt we had learnt a great deal and would handle it very much better. Our lives now revolved around child-related activities, so the change in lifestyle would not be so dramatic.

Alexander had been conceived without any assistance. By now I was 35, but still we did not expect much difficulty. However, after about a year with no success at conception, I consulted my GP, who referred me to a specialist. On the first visit the specialist put us on the in vitro fertilisation (IVF) waiting list, which was around one year long. At the time, this wasn't a decision we thought much about, as it was a long way off and we hoped to conceive before then. The specialist did a laparoscopy and found everything normal.

After a year our turn came up on the IVF program, and we attended an information session in which the procedures used were described in a general way. Statistics on success rates were also discussed. Before commencing on the program it was compulsory to have a session with the social worker, who went over the procedures in more detail and described the activities involved, such as having blood tests, ringing at particular times for instructions, and so on. At no time were potential risks mentioned, apart from miscarriages, abnormalities in the child, and

multiple pregnancies. Our decision then to commence on the program was almost a foregone conclusion, as it was presented as the next logical step.

Prior to commencing on the IVF program I decided to have a mammogram and breast examination at the Epworth Breast Clinic. This decision was taken by myself with no recommendation from any doctor. The two GPs I had consulted about the lumpy and sometimes painful condition of my breasts had responded with reassurances that this was normal and the result of cyclic hormonal changes and so on. The doctor who interpreted the mammogram and examined my breasts said the same thing.

The first attempt on the IVF program, in August 1988, was using the gamete intrafallopian transfer (GIFT) technique, suitable for those with healthy fallopian tubes. For this attempt the normal stimulation methods were used, with clomid. The doctor who did the egg pickup and implantation of eggs and sperm (not my doctor) said there was a small amount of endometriosis sticking the end of one tube to the ovary. This meant that further attempts had to be done using the more common IVF technique of placing the fertilized embryos in the uterus. The first attempt was not successful.

A minimum gap of 2 months (i.e., one unstimulated cycle in between) was recommended between attempts, and being eager to get on with it I waited only the minimum time before the second attempt. This time I was asked by a sister if I was prepared to go on an experimental program, which involved being brought to a menopausal state

(i.e., nonfunctioning ovaries) using a drug called Buserelin, then having my ovaries “kick started” (their term) with further drugs. I asked whether there were side effects with this program and was told that the only side effects were those common to menopause (i.e., hot flushes, mood changes). Accepting this answer I agreed to proceed.

OVARIAN HYPERSTIMULATION

I sniffed Buserilin for 3 weeks, then commenced HMG injections as well until Friday, 21 October 1988. On Saturday I stopped the Buserilin and was given a 3000 ml HCG injection late on Saturday night so that egg pickup could conveniently take place on Monday. On Monday the egg pickup went ahead under a general anaesthetic, with no prior contact with either doctor or anaesthetist. Tuesday I was still quite ill from the anaesthetic, and by Wednesday my abdomen was extended as well. The embryo implantation was scheduled for Thursday, and I presented with nausea and an even more extended abdomen. I was examined by the doctor on duty for that morning, who decided my symptoms were not significant and went ahead with both the implantation and a further 1000 ml HCG injection. I went home.

On Friday morning the situation had worsened, but my doctor on the IVF team did not interrupt his consultation sessions for patients. I was told he would ring me in the evening. Becoming desperate, I rang one of the sisters administering the program and explained my situation to her. She intervened and my doctor rang me at lunchtime and recommended that I be admitted to hospital immediately. This I did, and commenced vomiting shortly afterwards.

On Saturday my abdomen became even larger and the vomiting worsened. I had an ultrasound in the morning and was later told that my right ovary was 11 cm in diameter (cf. normal size of 3.5 cm). My condition

worsened as the day wore on. I became dehydrated and my pulse weakened. One of the sisters attempted to contact my doctor but couldn't, so called in one of the other doctors on the IVF team who inserted a drip.

On Sunday my abdomen grew even larger, as if in full-term pregnancy, and I began to vomit blood. The IVF doctor on duty that day recommended that a HCG booster be given as this was the normal procedure 3 days after implantation. However, John requested that this be checked with my own IVF doctor, who said by phone that this was “the last thing I needed.” I did not have it. John, at this stage, was extremely concerned. I was barely able to talk, had difficulty breathing, and could not move due to the fluid build up in my chest, abdomen, and legs. All I can remember is the terrible nausea and thirst, and thinking that when I recovered the only thing I wanted out of life was to be able to sit in my garden and drink as much fruit juice as I wanted. In the evening my doctor saw me and called in the physician from the intensive care unit, who took over supervision of the drip and general medical condition.

The vomiting stopped on Monday, but I was barely conscious all day due to a shortage of some substance in my system. John thought I was going to die.

The following day my weight peaked at 61 kg (it was about 48 kg prior to the IVF treatment), and my abdomen measured 97 cm. I was able to sip a little water for the first time in 3 days. During the night my urine output (via a catheter) increased dramatically.

On Wednesday I was able to sip sweet black tea, and it was just about the best thing I have ever tasted in my life. I was given plasma in the drip, which had to be changed to the other hand as the vein had developed problems.

I continued to improve on Thursday but could not yet stand without assistance. The drip was removed in the morning.

During these few days both of my breasts

became completely hard, like two hard hemispheres.

On Friday the catheter was removed in the morning. Late in the afternoon I began to menstruate, which was a devastating blow as it indicated that all this pain and suffering had been for nothing. I had been told that with hyperstimulation there was a greater chance of a pregnancy, so in spite of everything there was always the hope that I was suffering with some chance of reward. With that hope destroyed I couldn't face another night in hospital, and insisted on being discharged. The sister had to wheel me to the car in a wheelchair but it was worth it to be home.

RECUPERATION

For the first week at home I was confined to bed. After that I gradually increased my activities at home. I had to wear borrowed maternity clothes as my abdomen was still very extended. I had an ultrasound 12 days after I went home, and my right ovary was now down to 6 cm diameter, a big improvement on the 11 cm 18 days prior. After 6 weeks I was able to return to work.

During the time when I lay in hospital, I knew that I would never risk putting myself through such an experience again. When I felt that I had recovered, still I was not tempted to change my mind. Although I had one child, my desire for another was the dominant theme of my life. I wanted another child for myself, I loved my son so much I wanted more, I wanted a sibling for my son, I did not want him to spend his life as an only child. These feelings did not diminish, and I still live with them today, but I knew that I could not risk my life again. Not only did I not want to go through that experience again, but for my son's sake I could not put my health in jeopardy.

My opinion about the standard of medical care I received during the whole IVF experience was very low. I wrote a letter to the

manager of the infertility centre expressing the following concerns:

No mention was made of possible side effects other than menopausal symptoms; no discussion of things that could go wrong took place, meaning that women cannot make informed decisions.

Even though I was on an experimental regime with a new combination of drugs with which the Centre had little experience, no attempt was made to monitor the effects of the drugs after egg pickup was ordered: that is, after further monitoring would have no effect on the "success" (probability of pregnancy) of the procedure.

No continuity of care or responsibility could be provided by a system that rotated doctors through every half day. In my case this delayed diagnosis, as each time I was seen by a doctor who had not seen me before and needed to take no responsibility as someone else would be on duty the next half day. No doctor appeared to be watching out for hyperstimulation. The delay in diagnosis led to administration of drugs that exacerbated the problem.

The program was run like a production line. Procedures were rushed and there were huge queues and hours of waiting each morning.

The manager responded with an apologetic letter admitting some responsibility. Since then I believe they have changed the system to extend the length of time each doctor is responsible for the in-patients, and numbers accepted on the program have been restricted to reduce the queuing times and allow each patient to be treated with more care.

For me, the changes were too late. Four months later I was given a diagnosis of advanced breast cancer.

CANCER DIAGNOSIS

Commencing 3 months after the IVF attempt, I experienced severe nausea and vomiting each time I ovulated. This continued for 3 months, culminating in a return to the IVF ward as an in-patient. My GP believed that I was reliving the trauma of the hyperstimulation each time I ovulated, and that the illness was psychosomatic. I believed it was a direct result of the IVF attempt, either a continuing effect of the drugs or some kind of ongoing hormone imbalance caused by the extreme state to which my body was pushed. I placed responsibility for the diagnosis and treatment on my own IVF doctor, who took it somewhat reluctantly. Other doctors in the IVF team simply laughed at me, saying there was no possibility that there was any connection between my current condition and the IVF experience. This latter attitude incensed me: I could not believe that doctors involved in experimental treatment using powerful drugs could have such closed minds.

On the third occurrence, while in hospital in an acute state, my IVF doctor called in a specialist physician, who finally diagnosed breast cancer. It was not an easy diagnosis. Although both breasts were completely hard, this was said to be an ongoing effect of the hyperstimulation, and a second mammogram indicated no malignancies. However, after a positive bone biopsy and exhaustive tests, breast cancer was confirmed.

Once the diagnosis was made, I was no longer a patient of the IVF doctor. No contact was made at or after the diagnosis. I did not pursue this myself at the time, having many other things to deal with. However, it concerns me that, as far as I know, I am not registered with the IVF team as a patient with cancer diagnosed soon after IVF treatment. No details of my case (e.g., hormone receptivity) have been passed on to the IVF team.

I have thought much about the role that the IVF treatment played in the development of my cancer. There is no doubt in my mind that it played a significant one. My tumour is strongly hormone receptor positive, highly responsive to estrogen withdrawal. It is therefore difficult to accept that a massive overdose of estrogen would have no effect. I have had differing opinions on this from doctors, but most believe that the IVF treatment was significant in the development of the malignancy.

Undergoing IVF treatment was a decision I made out of a strong desire for a child. I understand and accept that things can go wrong. I do not expect doctors to be infallible. However, I do expect doctors to be honest and open-minded. I expected to be informed of the risks and I expected to be given competent medical attention if something did go wrong. I expected follow-up care whether the IVF attempt was "successful" or not. These expectations were not met.