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1. Introduction

Thank you very much for this introduction, and also thank you very much Robyn Rowland for giving this excellent contextualisation of what I'm going to say next. I want to start with a quote.

'No one ever talked to us about our experiences in the program, I mean the psychological side of it. Doctors don't place a great deal of importance on you. For them you are just X, just another number.'

This is what one of the women in my study said to me when I met her, and I thought this would be a good way to begin this talk both to point to the importance of doing research on the experiences of women on IVF programs, and to thank the Australian Federation of University Women who awarded me the Georgina Sweet Fellowship to do a pilot study on this subject.

Let me add immediately that this evening I will only be able to skim the surface of the wealth of responses that I'm getting and that because in the meantime 1 have successfully applied to become the post-doctoral research fellow at Deakin University, the project began with your help has expanded into a longer-term study, which I will continue upon my return to Australia in September. - Having said this, what am 1 doing in my study?

2. Methodology

It is becoming more and more public knowledge that IVF programs are not doing for infertile people what they were advertised for ever since the birth of Louise Brown, only in '78, it seems ages ago, well it's not even ten years: On the contrary, and despite the few women with babies in the media, 85% - 90% of all women on IVF program will leave without child. This is why 1 believe that it is very important to learn about the experiences of these 'unknown' women because I believe that they are more representative of what the programs do and what they don't, than the success stories in the papers.

But how does one find such women? I decided against going through the IVF clinics themselves, but appeal to women who have dropped out of IVF programs by an advertisement placed in The Age and the Herald.

The result is very positive. So far over 30 women have participated in my study, and the number is constantly growing because a lot of them refer me to other women they know who have been on IVF programs and for whom it hasn't worked. Participation consists of filling in a long questionnaire of 35 pages, and many women then agreed to a follow-up interview which usually takes 2-3 hours. I will in this short time just give you a feeling of what I asked them and what the responses are.

But before this two other points: firstly, about the nature of my research. What I am interested in most is how IVF affects women as human beings in their, in our own rights. In other words, how do they, how do we perceive what is happening to our bodies? How does it affect their bodies and selves, or sense of self-identity, if you prefer, and why are they doing it. In other words, the focus of my research is women-centred, rather than focussing on the foetus or the child. I believe such a research approach is sorely needed for as Robyn has pointed out, it is undoubtedly women who have to bear the burden on IVF programs; who go through the hormonal bombardments on a roller coaster of emotions; hopes up, hopes down, hopes up, hopes down, as one women in my study said.

Secondly, I want to add immediately that what I am doing now is probably the emotionally most difficult piece of research I have ever done in my whole life. And that on various occasions, if I could have done it, I would have taken this baby out of the basket and handed it to the woman I was talking to, so passionately do some of them want a child, and so devastated do they feel after the IVF program. This passion however, this desire to have children makes these women an extremely vulnerable group in the hands of doctors and

scientists who use them as experimental subjects. Having said this, I want to add immediately again that this does not mean that I see these women as weak or incapable of making decisions. Rather, the combination of wanting - or believing to want - a child and on the doctors'/scientists' part, the absence of knowledge of what infertility is, and why IVF works or doesn't, and the often greater interest in the advancement of science (and one's own career, I should add!) than the infertile person, plus a heavy dose of contempt for women, makes it extremely difficult to say 'No, I won't have IVF'. In fact, in the course of doing my research I have come to believe that IVF is no new choice for women, but that, on the contrary, it is a new form of coercion. A coercion into medical experimentation - and the short and long term consequences for IVF women and possibly their children and for all women as a group, are not yet clear at all. Now I shall try to substantiate this statement with the following evidence from my research.

3. Findings

A. Infertility

First, some words on infertility. Infertility is indeed - can indeed be - a most painful experience. In the words of one of the participants in my study

'I felt emotionally distraught, worthless, extremely upset, angry, it was bitter disappointment, social rejection - a feeling of being incomplete.'

What's more, it carries with it an enormous stigma. Infertility is considered a disease and people that are diagnosed infertile either receive condescending or pitiful remarks, or are coached into trying whatever they can. As one woman remembered

'There's one lady at work who's got three kids and she just won't have the infertility. She says, look, I've got a friend who had her first baby at forty, and you've still got four years to go, and you know, you're not to give up. And I say 'yes, but I'm sick of it, you know, it's been thirteen years and I've had enough.'

The causes of infertility however, are often unknown. Even if infertility is diagnosed as blocked tubes, this can be the result of untreated pelvic inflammatory disease, which in turn often comes from IUDs or infections, often to do with heterosexual activity. In other words, it is as much the man's doing, on the woman's body, when she ends up having an infection. But this is never mentioned, and in fact, two thirds of my responses, two thirds of my women respondents (I have not talked to men actually) felt guilty for it. As one woman says :

'I felt guilty, I knew my husband wanted children. Pelvic inflammatory disease carries a certain stigma much like venereal diseases I think and we both have to go through a lot of trauma on IVF. 1 felt I shouldn't be putting him through it, even though he wanted to.'

So many women offer their husband a divorce. Other guilt feelings include previous children that have been given up for adoption, previous abortions, having one's tubes tied at an earlier point in life. In addition to a huge variety of female infertility there is also male infertility. Most of the men have a low sperm count, and in 20-30% idiopathic infertility. I give you these figures although I know these numbers do not mean very much because of error, they're really made up for whose purposes it suits best. But never mind, between 20-30% idiopathic infertility is diagnosed which means no one knows why either egg or sperm do not produce an embryo, or why the embryo does not implant itself in the woman's womb. (Just as an aside, because I have the question in my questionnaire, only one man in my study is reported to have felt guilty for being infertile.)

The women who finally come to IVF comprise all these various 'forms' of infertility. It is generally not known that women with tied tubes are on the programs too. They are not infertile, but they might (although I cannot prove this) add to the success rate of IVF. In other words, for real infertility, there might even be a lower success rate than 10-15% which is something that we need to look into more closely.

The other women who have a diagnosed infertility have usually years and years of pre-IVF horror stories to tell about infertility treatments that last for months and months. Just one example:

'Firstly, I followed graphs to show ovulation restricting intercourse to fertile times; then referral to gyno. First gyno, again, graphs about fertile times, then tubular X-rays show blockage. Second gyno; laparoscopy, found endometriosis, six months Danocrin which cleared endometriosis. Clomid for six months and ultrascan to see whether I was ovulating, monthly blood tests to check ovulation and planning intercourse at peak, after intercourse mucus tests and when all that failed AIH - artificial insemination by husband.'

Or another woman which went on for months and months:

'First mucus tests on me; second mucus plus sperm tests; third laparoscopy, fourth salpinogram, dreadful. Tubal surgery, DREADFUL, microsurgery, more sperm and more mucus tests with donor controls. Naturopath and finally IVF.'

I emphasise these pre-IVF treatments which not surprisingly often place enormous strain on the couples' relationships and sometimes cause more damage to the woman's body than the repair they do, because it is with this heavy baggage that they all begin IVF. And IVF, with the glamour displayed in magazines promises hope once more. As one woman put it : 'We felt it was the last opportunity open to us.'

B. The IVF Procedure

You know already that IVF does not fulfill the promise in most cases. But what are the actual experiences on the program? A number of points - or complaints rather - surface with great regularity. Firstly, generally with very few exceptions there is an absence of information on what being on the program means. It is either not given at all, it is given with great condescension, or it is given too much at a time so that no one can take it in. For instance, only one woman actually was told about possible side effects from the massive doses of hormones that were given, and yet we do know about the side effects. We do not have, as Robyn pointed out, the short and long term studies, but we actually do know about the side effects when these drugs are given infertility treatment. OASIS, a group for infertile people in Adelaide, puts out a sheet which lists a whole range of side effects and I haven't got time to read it out, but for clomid, which is still one of the most used fertility drugs, the side effects are :

'hot flushes and abdominal discomfort or bloating, blurred vision, nausea, nervous tension, depression, fatigue, dizziness and lightheadedness, insomnia, headaches, back problems, and breast soreness. [1]

I should point out immediately that many women in my study actually complained of all or some of these side-effects long after they left the IVF program.

The other complaint is that there is no independent counselling prior to commencing IVF. Sometimes what is offered is in-house counselling, but 24 hours prior to starting on the program, for which you have been on the waiting list for two years. Would you voice doubts about whether you should be on IVF, or whether your marriage is good and stable, or whether you may actually indeed be able to cope with the fears that you actually have, of once more 'failing', which is not the woman's terms, but it is the doctors' terms [2] .

This lack of both information and counselling prior to and during IVF continues during the procedure. As one of my women remembers:

'I was shocked at the number of women on the program. I felt very unspecial, like a laboratory rat. I felt that my emotional needs were not being met by nurses and specially by my doctor. He hated me questioning his motives and would often pat my head and say "you don't need to worry about things like that". I felt I had to shut up or risk delay on the program.'

Another woman whose husband had a low sperm count - in other words, she was perfectly OK - remembers how she was chastised by a nurse for not producing more ripe egg cells : 'Infertile women do better than you, what's the matter, can't you try a bit harder.' Such comments show that women on the program are

very often seen as nothing more than machines with some defect which needs ьbe fixed up. As one other woman remembers:

'I felt like a Fresian cow waiting to be experimented upon. I did not feel like a person after talking to Professor X. The team aren't interested in people, only in science.'

And another says :

'I was horrified at the demands made on the woman and that I had no other women to talk to. I felt so isolated and freakish and lonely, and an underdog or even a victim.'

Now, on the good side of things there are a few other women who got support from all the women on the program. Also there seems to be some evidence that marriages do actually improve during IVF. (But I want to be very careful with this as it contradicts information from other countries that says that the IVF procedure would really break up marriages.) But in my study there are some women who say that their relationship has become stronger. They now know - so they say that they can survive practically everything after the 'failing' on the IVF program.

In fact talking to the women in the survey I am surprised that any woman manages to 'produce' a baby. Because this is really what IVF is, a 'baby production line' as one woman put it!

The emotional stress to make it to the daily appointments, to have your blood taken, to assess the hormonal level, and have the growth of your follicle monitored, often an ultrasound - no safe procedure either -and done with a very uncomfortably full bladder, the sheer pain and embarrassment when your veins won't come up for the neverending blood tests. The unpleasantness of it, the nervousness to perform well, the anxiousness ... and these are all words used by the women. And anxiousness above all, of again, not being a failure, as one woman remembers: 'My nerves were tied in knots.'

In about three quarters of all cases, it is the embryo transfer that does not work. The way the next woman remembers her feelings when her periods started sums it all up:

'I can't describe the feelings accurately, but 1 think it is akin to bei.ng grief stricken. Also the feeling of "Oh God, I've got to go through all this again next cycle" It is utter despair and extreme isolation. You feel you are a dismal failure.'

However, while the women feel like failures, indeed are made to feel like failures, indeed are made to feel like failures, things are not all that wonderful on the doctors' side. I could fill a whole evening with horror stories that I've been told, many of which might suffice to lay a lawsuit at the IVF staff's hands. Firstly, there is a simple lack of human decency going on as the following example shows:

'I also remember the first embryo transfer I had. At the time there were visiting doctors from IVF programs around the world, and I happened to be one of the guinea pigs going in for the transfer on the day they were at the hospital. It is embarrassing enough lying there with your legs up in stirrups without a roomful of people staring at you and with a huge spotlight (theatre light) shining on your genitals! When my doctor said to me that after that day I would have an "international fanny" I was really annoyed at this remark, and the innuendo that I should somehow be thrilled at the prospect of being seen by all these international doctors.'

But then there are other things that happen on the program: eggs are lost somewhere, eggs are cooked, meaning something goes wrong. Eggs are mixed up in the lab and on more than one occasion, doctors are too late for the women's ovulation in order to perform the egg recovery. Now I want to remind you of what Robyn Rowland said all about the hormonal intake, what women have to do,

and that the ovulation time has to be really very precise otherwise it just doesn't work. In one example the woman actually rushed from Geelong to Melbourne to get there at 6 o'clock in the morning, when she felt she started to ovulate but the doctors were not there. Now that is of course a problem… To give you another example, in a conference on IVF, a doctor talking about the onset of ovulation opened his talk with showing a slide of a beautiful French countryside and said, 'Well, we doctors want holidays too, therefore we actually have to find means to get these women on IVF programs to perform at the best time.'

I believe that this is the whole gist of the argument that they want to get across: that we are made to become more and more machines consisting of parts that have to produce the 'product baby'. Unfortunately, as we know, in most cases it won't work.

Well I think I had better stop here. There would be much more to say about the time after IVF, and how, NO, but absolutely no counselling is offered to deal with the grief and the feelings that this 'last hope' has gone too. There are IVF groups, for instance a group called IVF Friends, but some women said to me they're not interested in that group, because all it does is to keep their minds on IVF. What they really need is support to come to grips with their infertility which is not what IVF does.

Coming back to the beginning of my talk, I want to repeat that I do not -emphatically not - believe that IVF is in any way helpful to solve the problem of infertility. Indeed I believe it prolongs the agony for many women who will now have to come to terms with the fact that they will never have their own biological children. I believe it further reduces women to machines, (conveniently also taking them out of the labour market and/or making them more economically dependent on their husbands). IVF, to put it bluntly, creates a new myth of motherhood: perhaps now - so the myth goes -even you infertile women or part of you, can do it ... : produce a child. But, 'at what price?' is the question that is never asked, nor why life without biological children isn't a possibility too.

Perhaps we'll have time to discuss what could be seen as alternatives: Research into the prevention of infertility; other, more natural infertility treatments etc. And easier ways to adopt an area, 1 think, with. a lot of problems. As IVF stands now, I believe it does not serve women's needs as I have identified them at the beginning of my talk as a sense of self, a right to one's dignity as an autonomous human being, a woman. One of the participants in my study actually used this word. She said

'I had enough of being the subject of medical experimentation. I felt it violated my dignity I had to stop for my sense of self.'

To repeat myself, I believe today's medicine and science create the possibility for making women feel like failures. The next scene already being set up concerns IVF children. Following from a Swiss article women are already now blamed for specific problems that IVF children might develop. The scientists however, use increasing numbers of women who queue on the programs to have access to experimental material and if they are allowed to continue embryo research, the ghost of genetic engineering, from genetic screening to therapy, and routine ante-natal tests is conjured up.

But let me end on a positive note. Many women clearly analyse what goes on during IVF, and some stop taking it. As one woman describes her experience:

'After attending hospital for 21/2- hours one day, and being prodded and poked all that time, blood tests, ultrasound, needles, I eventually got off the table and said "tell the doctor he can stick this up his jumper." I knew weeks of that would be untenable, especially after having to get up at 5.00 am to travel two hours each way to hospital, AND PROBABLY NO BABY AT THE END. What a joke. I feel so sorry for the women who have to use IVF.'

I can only hope that this piece of research will help to encourage more women to do the same -or even better, to stay away from IVF and seek to come to terms with life without their own biological children.