## Feature

# Failures of reproduction: problematising 'success' in assisted reproductive technology

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This paper scrutinises the many ways in which 'success' is portrayed in representing assisted reproductive technology (ART) services and illuminates how these definitions differ from those held by participant couples. A qualitative approach informed by feminist perspectives guided this study and aimed to problematise the concept of 'success' by examining literature from ART clinics, government reports on ART, and by analysing narratives of couples who have accessed ART services. As many ART services have varying definitions of 'success' and as statistics are manipulated to promote further patronage of ART services, the likelihood of 'success' is often overstated. This paper is concerned with the effects this promotion has on the participants. We suggest that this very mobilisation of statistical success changes the ability of those who access ART services to make productive decisions about themselves inside these treatment regimes, as the basis for decision-making is hidden by the way numbers, objectivity and clinical reasoning operate to maintain participation in the program. In such an operation, the powerful mix of hope and technology kept participants enrolled far longer than they originally planned. Moreover, how success rates are manipulated raises ethical issues for all involved: clients, counsellors, and nursing and medical professionals.

Key words: assisted reproductive technology, biostatistics, feminist narrative analysis, infertility, success.

Technologies such as assisted reproductive technology (ART) are located centrally within new developments in technology that foster a sense of control over human reproductive capacities. This paper stems from a doctoral study, which analysed the narratives of couples' experiences of childlessness despite treatment for infertility. Our aim in this paper is to problematise the concept of 'success'. This will be done in two ways, initially by examining the literature about ART and the literature that presents ART clinics to those who may access this technology. A further source of information about ART came from interviewing couples who accessed ART services without the positive outcome of a biological child and analysing their narratives.

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This paper seeks to highlight the problematic definition of 'success' to nurses and other healthcare professionals working in the field of ART. It is hoped that this knowledge will improve current practice, and reduce the negative effects of treatment failure to childless couples. Through expanded knowledge, nurses and other healthcare professionals will be better equipped to provide realistic care, conveying the possibility of treatment failure and introducing various options for a fulfilling life in the absence of biological parenting.

There are multiple ways of counting what could be called success as well as varying meanings associated with the use of the word success, even within ART itself. To explore the underlying effects of these differences, we explored the portrayals of 'success' in official reports and ART clinics' information. This framing of ART is then set against the stories told by couples who participated in this research. The stories from the couples provide a different perspective and,

through engaging in an analysis of these sources, the conflicting constructions of success are highlighted.

# FRAMING ART AND ITS PLACE IN CONTEMPORARY INFERTILITY TREATMENT

Infertility affects as many as one in six Australian couples at some stage of their reproductive lives (The Fertility Society of Australia (FSA) 2005). Currently, infertility is simply defined as the failure to achieve a pregnancy after 12 months of unprotected intercourse or the inability to continue pregnancy to a live birth (Gibson and Myers 2000; Monash IVF 2001; FSA 2005).

Since the birth of Louise Brown, the first baby born as a result of *in vitro* fertilisation in 1978, infertile couples' hopes are magnified as to the possibility of 'achieving' biological parenthood with the assistance of ART. Franklin (1997, 209) states that 'technology can provide what nature fails to deliver: it can bridge the gaps, make the connections and assist nature in doing what it should have done "naturally"'. However, although ART may be available, it provides no guarantee that all couples will be able to 'achieve' parenthood. Apart from the obvious fact that availability does not necessarily signify accessibility (as ART is a costly and time-consuming process and is not a viable option for all infertile couples), the chance of taking home a baby for those who access this technology remains small.

# METHODOLOGY AND THE IDEAS THAT INFORMED THIS STUDY

A qualitative methodology informed by feminist perspectives was used for the purpose of this study. A key feminist theme underpinning this research is 'the personal is the political' meaning that 'the system' is embedded in everyday life (Stanley and Wise 1983). The presence of 'the system' can be notably observed in the lives of couples who access ART. For instance, an aim of undergoing ART is to become a family. The personal urge to become a parent is an urge socialised into people early in their life. This social aim is therefore both personal and political in that this aim is set through social structures about the institution of family. Moreover, the act of procreation has traditionally been a private and personal issue. However, the introduction of ART has brought procreation out of the bedroom and more clearly into public and political forums where judgements are made on the worthiness of couples or individuals to be parents, and also their right to access ART (de Lacey 1998; Rickard 2001). A further dimension that follows from taking a feminist perspective is that the concepts of self-disclosure and reciprocity

are integral to the study. To this end, the interviewer both disclosed her personal experience with ART and invested time in rapport building with participants. Throughout encounters the interviewer willingly engaged in a mutual dialogue with participants, creating a milieu of equality, and thus minimising the inequality of power between 'the researcher' and 'the researched' (Stanley and Wise 1983).

# Data collection strategies: texts, interviews and narratives

Two sources of data from the study are used in this paper. The documents explored that provided the textual data for the analysis of current and accepted measures of 'success' by ART services included formal reports by the Australian Institute of Health and Welfare (AIHW) National Perinatal Statistics Unit. These reports comprise data from all ART services in both Australia and New Zealand, and present a consistent record of definitions, various treatments delivered and outcomes of those treatments (Bryant, Sullivan and Dean 2004). Further to this, material pertaining to 'success' rates found on websites used to market specific ART services was critiqued. Definitions of 'success' throughout the documents were then compared to the understanding of 'success' provided by interview data provided by voluntary participants. These participants were five heterosexual married couples, who had been diagnosed as infertile and sought a 'cure' for their infertility by accessing ART. Each couple had accessed ART for approximately 9 years, and ceased this treatment without obtaining the desired outcome of a biological child. We acknowledge that couples who have been successful in taking home a baby with ART assistance may represent these services differently. However, this doctoral study sought to reveal the less publicised impact of ART failure on couples who accessed this technology.

Participants were recruited by an advertisement placed in a local paper and on an infertility support group website. Members of the public who had ceased ART and remained involuntarily and permanently childless were invited to participate in the study. Potential participants made contact by telephone or e-mail and were given further information regarding the study. For those willing to participate, appointments for meetings were made at a mutually convenient time and place. Individual conversations with both partners were audiotaped and then transcribed.

# Narrative analysis

To enhance understanding of participants' stories, the submersion of self in the text (as recommended by Anderson and Jack 1991) was necessary to allow individual voices and concerns to become obvious. This process involved reading the transcripted conversations multiple times while simultaneously listening to the audiotaped conversations, in order to obtain a comprehensive understanding of the content. Dominant stories within individual transcripts were identified by the emphasis participants placed on them, either by repetition or by expression. Subsequent to the identification of dominant stories within individual transcripts, those that were common, both within the dyads and between individuals, were identified. After the completion of this stage of identification, stories that best represented all participants' accounts were presented in the thesis.

For the purpose of analysing participants' conversations, this research drew heavily on work by Anderson and Jack (1991) who inform us of three ways of listening that enable us to understand a person's story. These are listening to the storyteller's moral self-evaluative statements, paying attention to meta-statements, and attending to the logic of the story. These three ways of listening allow the voice of the storyteller to be heard, allow us to examine the relationship between self-concept and cultural norms, and highlights an individual's awareness of a discrepancy within the self or between what is expected and what is being said. Frank (1995, 23) also influenced the analysis of participants' stories by encouraging us to think with stories rather than about stories, that is experience the story as 'affecting one's own life'.

#### Ethical considerations

Ethical approval for this study was given by the relevant institutional ethics committee (IEC). Participant information sheets were mailed out to participants prior to the encounter to ensure they had the opportunity to read and understand the purpose of the study, what was required of them, potential risks, benefits and costs to them and their rights as a participant. Prior to commencement of the conversation participants were asked to clarify understanding of the information supplied, before signing a consent form. Study participants were informed that they could cease the conversation, retract statements and/or withdraw from the study at any time. Pseudonyms and the distortion of other identifying features were used to enhance confidentiality.

# NUMBERS AND HOW THEY ARE MOBILISED TO TALK ABOUT THINGS

Quoted success rates are often ambiguous and may vary widely between clinics, with some boasting success rates as high as 78% (Hull et al. 1992). Factors such as age of treated

women, number of embryos transferred, number of cycles undergone, various techniques, and reason for infertility may be manipulated to enhance final published results. Most clinics though agree that the first IVF cycle holds a greater chance for success than does any subsequent cycle, live deliveries substantially increase as a result of fresh, non-donor cycles compared to other cycles such as thawed embryo and donor insemination cycles, and the increase in maternal age inversely relates to success rates for assisted reproductive procedures (Jansen 2003; Bryant, Sullivan and Dean 2004).

Statistics from an AIHW National Perinatal Statistics Unit report, for outcomes from the year 2000, allude to a much increased success rate for ART, with claims of a 21.2% clinical pregnancy rate per embryo transfer (Dean and Sullivan 2003). However, many of these include spontaneous abortions, blighted ovum and ectopic pregnancies. These bring the viable pregnancy rate down to 17.9%. The number of foetal deaths brings the success rate down to 17%, and with a further 1% of neonatal deaths, that is infants alive at birth but dying within 28 days of birth, the success rate, or the chance of actually having a 'take-home' baby, drops to 16%. Figures stating complications due to preterm births (which occur in about 25% of cases) are not included in this report (Dean and Sullivan 2003).

In light of information revealed by Hansen et al. (2002) that major birth defects are twice as prevalent in IVF babies when compared with those naturally conceived, and neonatal mortality in ART babies is significantly higher than the mortality rate for naturally conceived babies (Dean and Sullivan 2003; Bryant, Sullivan and Dean 2004), the way in which the term 'success' is used becomes increasingly problematic. In a Cochrane review Edi-Osagie et al. (2003) found that only six out of 23 studies on ART analysed reported live birth data and suggest this indicates haste on the part of the authors to publish short-term outcomes. These authors also found that the majority of studies analysed neglected to report negative outcomes such as miscarriage and warn that both 'sampling to a forgone conclusion' (Edi-Osagie et al. 2003, 9) and failure to report negative outcomes create an immense potential for bias.

The presentation of statistics in the AIHW National Perinatal Statistics Unit reports has recently changed to include recognition of all treatment cycles commenced in relation to ART 'success' rather than purely taking into account the number of embryo transfers performed. This revised representation acknowledges that not all treatment cycles have the favourable outcome of an embryo transfer; that is, some treatment cycles are cancelled for a variety of reasons prior to embryo transfer, including failed oocyte pick-up

(OPU), the failure of oocytes to fertilise, and unsuccessful thaws (Bryant, Sullivan and Dean 2004). While 'successes' in this report, for fresh embryo cycles, almost double 'successes' recorded for 1993, 'success' continues to be defined as a 'pregnancy', including the nonviable outcomes previously mentioned (Bryant, Sullivan and Dean 2004, 3).

# Countering success: experiential accounts of 'success' and 'failure'

Participant couples' definition of 'success' was different from those found in the above-mentioned literature. Success for these couples meant a live, healthy baby that they could take home. As illustrated by participants of this research, women often contribute to the 'successes' of ART while remaining 'failures' of reproduction. The asymmetrical way in which success and failure is apportioned means that women wear the failure of technology as well as the failure of reproduction, whilst ART bears all the successes. This is apparent in stories told by participants about their IVF miscarriages. By using a clinical pregnancy as a measure of success, that is evidence of pregnancy by clinical or ultrasound parameters, including ectopic pregnancy (Bryant, Sullivan and Dean 2004), their pregnancies were counted as ART successes even though the outcome of their pregnancies was negative. Anna recounts:

but by 12 weeks I had a miscarriage, so which was very, you know, sad obviously. But he <code>[IVF doctor]</code> kept saying it was ... it was 'his' success. Because I was on Clomid¹ and he'd done this thing, he'd cleaned out the tubes and all these kinds of things ... And I kept thinking to myself, well you know, I'm not sure how that equates to that, but okay if you want to class that as your success ... and he put that down obviously in his own records as being that was a success for him. So it wasn't a success for me, I can tell you, because I was pretty devastated.

This extract shows how this woman carries the burden of the pregnancy failure while ART and the physician were 'successful' at achieving the pregnancy. Although ART fails to ensure the pregnancy is maintained to term and results in a healthy baby, each woman continued to see that they carried the burden of failure on technology's behalf.

Rosemary's story conveys the sense of failure she felt after her IVF miscarriage:

And I recall after the D&C<sup>2</sup> the next morning ... um ... the nursing sister said to me, 'Your husband's coming up to see

you'. And it was this really funny thing and I said, 'well I don't want to see him, I don't want to see anyone, okay, just close the door when you leave'. And I'll never forget James coming in with a great big bunch of flowers and that's the last person in the world I wanted to see. I think because I felt like I'd let him ... failed him too, like you feel like you're the one that's lost the baby because it was inside you and it's pretty hard not to feel like that.

For a woman to be considered a 'success' in reproduction, she must do more than prove she is able to continue a pregnancy to a live birth. As well as delivering a live baby, she is expected to take a live baby home. This definition of 'success', and not the ART definition, is undoubtedly the one firmly implanted in the minds of those who access such technology, and indeed in the minds of society in general when hearing of the improved success rates of ART. Moreover, we suggest it is this difference in definitions of success that contributes broadly to the many misconceptions society has regarding actual outcomes of ART programs.

## There was always the hope

The very reason that couples access ART treatment initially is often based on societal expectation, that is, that they become parents. The hope that technology will provide them with the much sought-after baby is evident in Greg's story where he shares,

There was always the hope that there would be this medical solution to the problem. And through that process (IVF process), I mean, the thing is we were encouraged, we did have feelings of hope that things would work.

Societal expectations regarding ART outcomes have been fashioned, according to Shanner and Nisker (2001), by the media's portrayal of available technology, which accentuates positive outcomes, thus diminishing negative outcomes.

Societal expectation that ART will result in a 'miracle' baby is illustrated in Rosemary's story regarding her first IVF cycle. She tells of her family anticipating a pregnancy, as this is how they had seen ART portrayed in a popular women's magazine: 'And my family was all preparing for quads, you know, as they've seen in the *Woman's Weekly*'. With ART being represented in this light, the magnitude of the sense of failure at not achieving a pregnancy, even with the perceived miraculous assistance of ART, is exacerbated. Not only does the woman fail to conceive naturally, but she is also unable to conceive even though she has access to the latest technology.

Addressing the concept of hope in this context Franklin (1997) describes the image of a desperate and infertile woman metaphorically signifying hope (for the miracle of a child) and faith in technology (to be able to provide this miracle)

 $<sup>\</sup>ensuremath{^{\mathsf{I}}}$  Drug used in the treatment of ovulatory failure.

<sup>&</sup>lt;sup>2</sup> Dilation and curettage. An operative procedure that dilates the cervix to allow curetting of the endometrial lining. Commonly performed after miscarriage or spontaneous abortions.

(202–3). Franklin elaborates further, aligning this image with the unification of traditional family and faith in technology to improve the human condition (203). Therefore hope is not confined to the couple accessing ART but extends further to include 'the shared collective hope invested in the promise of science and technology' (203). In light of the importance of ART in this context, it is not surprising that these couples were encouraged to continue treatment even when their chances for 'success' were minimal.

Participant couples struggled to fit in with the ideology of the normal family that is defined as the 'nuclear family unit of a heterosexual couple and their biological children' (Andersen 1991, 235). Although these couples are not able to live the normative narrative they still strongly believe in the normative family ideology, having made a huge investment in technology in an attempt to fit in and *be in* the dominant story line. Throughout the treatment process, these couples often felt as if they were given false hope of a 'successful' outcome and therefore persevered longer than they otherwise would have. For example, Anna explains:

But you were made to feel like it was going to happen. 'No matter what, we've done the best job here, we've done', you know ... and it was great that they had but in hindsight now I wish I was told then what my chances were, because as you ... as it goes on in the story, I mean, 8, 9 years down the track, you know, they then start telling you ... your percentage chances of getting you pregnant, because they know that they're running out of time. But at that stage I was already quite low on time as well, you know, and I may have made other choices, if I had have known what was ahead of us and what the chances were.

Also, participant couples did not easily give up on the normative ideology of family. They continued treatment to prevent becoming outsiders, even to the detriment of their physical and psychological health. Moreover, the prolonged time these couples spent engaging with ART resulted in other life choices being denied to them, with the prolongation fuelled by the hope and desire obtained by aligned hope and socialised dreams of family life.

## **DISCUSSION: 'SUCCESS' BY NUMBERS**

Although Griesinger et al. (2004) point out that preterm birth can be a result of many factors outside the control of ART programs, providers of ART services remain willing to count any live birth as a success. Griesinger et al. advocate that, apart from the medical profession needing to record various broader outcome measures, 'gestational age at delivery does not seem appropriate to measure the professional competence of a centre or programme' (2004, 1241). Considering that the likelihood of survival is directly proportional to

gestational age (Draper et al. 1999), it is remiss of ART services not to take into account the number of complications and neonatal deaths, particularly in light of success rates being used to promote the status of the clinic (Griesinger et al. 2004). Apart from this, it seems that the information clinics are willing to share with their patients regarding outcomes remains limited. Outcomes relating specifically to types of infertility, age and varying procedures may give couples a greater indication of what they consider their chances of success — that is of taking home a healthy baby.

The focus of ART clinics does not go beyond conception and embryo transfer. They may follow up a 'result' in terms of its 'success' or 'failure' without expressing concern for women who have conceived, or the health of the baby they carry. It is in such a context that Wennerholm and Bergh (2004) agree with Griesinger et al. (2004) that the condition of the patient primarily influences preterm birth. Sociological factors, past obstetric history and complications of pregnancy are identified as salient risk factors for preterm births (Griesinger et al. 2004; Wennerholm and Bergh 2004). A focus on maternal condition shifts blame and serves to absolve IVF clinics from 'failures' of this kind. However, the reason(s) why the couple presented for treatment need to be taken into account. Only some that use ART are unable to conceive, and in these cases successful conceptions may be reasonably counted as ART successes. However, if maintaining a pregnancy to term was the primary reason for accessing ART, then, in this case, early labour and a preterm birth between 20 and 37 weeks' gestation cannot be considered a success but should be counted as an ART failure.

ART clinics remain divided on what should be determined as a numerator of success. Although some clinics agree that the safe delivery of a baby (or babies in the case of multiple births) at term is the ideal measure of success (Buckett and Tanner 2004; Heijnen, Macklon and Fauser 2004), live birth per embryo transfer cycle commenced remains the most widely used measure of success in Australian and New Zealand reports (Bryant, Sullivan and Dean 2004). The best measure of success according to Min et al. (2004) is the birth of a single live baby at gestation of 37 weeks or more as a result of a fresh, non-donor cycle in which ovulation drugs are administered. Whilst the birth of a single live baby at 37 weeks' or more gestation is indisputably a success, the starting point of the measure consisting only of fresh, nondonor, stimulated cycles again falsely elevates what a couple would class as a success. Fresh, non-donor, stimulated cycles have significantly greater successes than frozen cycles (Bryant, Sullivan and Dean 2004); therefore, to provide a more accurate indication of success rates all cycles, whether fresh or frozen, and donor or non-donor, require counting.

How statistics operated in presenting numerical 'facts' may make a difference to adherence to an ART program. Statistics, Hacking (1991) suggests, appear to tame chance by presenting probabilistic certainties. For instance, IVF Australia (2005) acknowledge that 'success' is a 'take home baby'; however, graphs on this site show results for clinical pregnancies per embryo transfer at a 50.4% 'success' rate for women aged 22-34 years. Clearly, as what counts as success shifts, and because the aims of treatment are actually different, the clients of the services will never share the views with the clinics as to what constitutes success. When confronted with this shifting of definitions and accounting, the need for truth in advertising has brought an attempt to have a separate arbiter to provide objective numbers and facts and to remove the clinics from the calculations of success rates. The AIHW report now uses the Australian and New Zealand Assisted Reproduction Database (ANZARD), which 'allows improved consistency in data definitions, robust linkage of pregnancy outcomes to treatment characteristics, and more efficient collection and transfer of data from fertility centres to the NPSU' (Bryant, Sullivan and Dean 2004, vii). However, it is also clear that the collection of statistics and what counts as success is set so as to obscure the low success rates for live birth or the further decline in this success with age (Rose 2005).

## **CONCLUSION**

As ART services have varying definitions of 'success' that are disparate to those held by participant couples, and as statistics are manipulated to promote further patronage of ART services, the likelihood of 'success' is overstated. The embellishment of ART as a successful cure for infertility is at least partially responsible for couples persevering with treatment for prolonged periods of time. ART services giving unrealistic impressions of couples' chances of reproducing a biological child remain short of the moral requirement for informed consent.

Individualistic consideration regarding a couple's chances of success will serve to encourage a more realistic expectation of treatment, thereby possibly preventing prolonged and futile investment in technological 'cures' for infertility and childlessness. Furthermore, couples may be empowered to make the decisions required to pursue either an alternative way of becoming parents, or living a different narrative from the norm and following other life aspirations without children. All causes of infertility being subsumed under the one umbrella term is problematic too. Clearly, ART's claims to provide a 'cure' for all infertility, irrespective of cause, is debatable and contentious, as attested by many authors as

well as the participants in this study. Moreover, this technology is not infallible. While claims for 'success' are inflated by ART services, suitable understanding as to what counts as success for the couples who access this technology does not become part of the calculation. This serves to compound the service user's sense of failure and disappointment in ART when it fails to produce the take-home baby they desire.

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