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Children of assisted reproductive technology: Medical and psychological issues

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ABSTRACT

Since the birth of Louise Brown in 1978, thousands of children around the world have been born as a result of in vitro fertilization and other assisted reproductive technologies (ART). This paper will review the literature on the health and psychological well-being of ART children, discuss psychological issues unique to ART families and suggest counselling strategies to mental health professionals working with these families.

Key words: In vitro fertilization, Assisted reproductive technologies.

Introduction

Louise Brown, the world's first baby conceived outside the womb through in vitro fertilization (IVF), is now a healthy young adult. Since her birth in 1978, thousands of babies around the world have been born as a result of this remarkable process. The announcement of her birth more than twenty-six years ago –that she was healthy and, above all, *normal*– raised the hopes of infertile couples everywhere. At the same time, the fact that she had been conceived «in a test tube» caused worldwide controversy and concern about the moral and ethical issues – the «Pandora's box of possibilities» that the development of this technology evoked (Edwards & Steptoe, 1980). For example, in 1979 Joseph Califano, then Secretary of the United

States Department of Health and Human Services, expressed the following concerns: *«Does the perfection of these techniques create a potential for abuse so severe, that the Federal Government should not support or should strictly limit its support of the research? Can techniques of in vitro fertilization and transplantation of the embryo damage the resulting fetus and lead to abnormal children? Will this research lead to selective breeding, to attempts to control the genetic make-up of offspring or the use of "surrogate parents", where, for example, rich women might pay poor women to carry their children?»* (Califano, 1981).

Since 1978 the controversies surrounding IVF have not abated. Indeed, they have become considerably more complicated by the development of other assisted reproductive

technologies, such as embryo cryopreservation, oocyte donation and intracellular sperm injection, to name but a few. The joy and anticipation generated by this marvellous treatment—offering the possibility of pregnancy and parenthood to participants heretofore unable to conceive—is tempered by the ethical controversy that often accompanies them. For example, embryo cryopreservation, while offering programs (and patients) the opportunity to preserve rather than discard or feel compelled to implant too many embryos, has led to the problem of embryos being «abandoned» by couples no longer interested in pursuing treatment, and, subsequently, «stockpiled» by programs reluctant to destroy them (Edwards & Beard, 1997; American Society of Reproductive Medicine, 1998; Klock, Sheinin, & Kazer, 2001). Oocyte donation, initially developed as an ingenious solution for young women with premature ovarian failure, who could not supply their own ova, has in recent years become a common treatment for post-menopausal women seeking a pregnancy (Lutjen, Trounson, Leeton et al., 1984). At times in the United States this has led to the spectacle of older women paying large sums of money to younger women for their eggs (Marshall, Emrich, Hjelm et al., 1999).

Developments in IVF have resulted in successful treatments for male infertility as well. With the introduction of intracytoplasmic sperm injection (ICSI), men with low sperm counts, even men who are oligospermic or physically unable to ejaculate, such as quadriplegics, can now become fathers through this technology (Van Steirteghem, Liu, Joris et al., 1993). This treatment allows for posthumous sperm extraction as well, leading to the controversial phenomenon of women seeking pregnancy using the semen of their dead partners (Hall, 1997).

Thus, in the years following the birth of Louise Brown, treatment that began as a remedy for blocked or missing fallopian tubes in women has expanded to include a number of other

treatment possibilities, often resulting in unanticipated possibilities, as well as controversy. As a result, there are now many thousands of children whose birth resulted from these innovative technologies and for whom there is no precedent. Much attention has been devoted to concerns about the euphoria and dysphoria associated with the experience of IVF, the emotional stress of the treatment and the impact of infertility and ART on couples' sexual, emotional, financial and marital life (Mahlstedt, 1985; Mazure & Greenfeld, 1989; Berg & Wilson, 1991). Perhaps, because infertility treatment centers are, by definition, geared toward pregnancy and the patients are typically childless couples anguishing over their inability to conceive, both are usually focused on the treatment itself and their fears that the treatment will end in yet another failure. Perhaps this is the reason that there is often rather less focus on the children resulting from ART.

What do we know about the health and well being of these children? Initially concerns were that ART offspring might be physically harmed by this process (Edwards & Steptoe, 1980). These concerns diminished somewhat once it was clear that Louise Brown was healthy, but the treatment is not without challenging issues. For example, the transfer of multiple embryos has led to an increase in multiple gestations, which, in turn, has led to increased problems with low birth weight and premature birth (Lipitz, Frenkell, Watts et al., 1990). Recent evidence suggests that ICSI births may result in an increased incidence of birth defects (Hansen, Kurinczuk, Bower, & Webb, 2002).

What do we know about the psychosocial health of these children? Are there emotional and developmental issues specific to children born through these treatments? For example, do their parents typically regard them as so precious, that they are overprotected and coddled? Mental health professionals working with couples entering programs of IVF and ART are often the first to initiate a discussion with them about their

potential children and their concerns for the future. This paper will address the ongoing changes in ART that affect families, including the children created as a result of ART. It will include a summary of studies of the medical and psychological well being of children conceived through these birth technologies. It will also discuss psychological issues faced by ART families and make counselling suggestions for mental health professionals working in this capacity.

Literature review

Definition of terms

ART: Assisted reproductive technologies, including IVF, ICSI and gamete donation

DI: Donor insemination

IVF: In vitro fertilization

ICSI: Intracellular sperm injection

LBW: Low birth weight

VLBW: Very low birth weight

Studies of physical health of ART children

Several European countries have established voluntary birth registries and have closely followed the birth of children conceived through IVF. The first such studies came from the United Kingdom in 1983 (MRC, 1990). Assessing the health of children conceived through IVF, the authors gathered data from 1,092 deliveries. Results showed that 19% of the deliveries were twins and 4% were triplets or higher order pregnancies. IVF patients had more pre-term deliveries, more low birth weight, even when multiples were excluded from the analysis. The rate of stillbirths and neonatal death was about twice the national average for IVF babies, with 11.7 per 1,000 for singletons and 39.7 per 1,000 for twins. The rate of congenital malformations among the IVF children was 2.9%, which was in keeping with the national average. The authors

speculated that the high rates of pre-term births and LBW were due to maternal factors or infertility related problems. The higher rate of perinatal mortality was seen to be due to the higher rate of multiple pregnancy.

A voluntary birth registry managed by the French National Institute for Health and Medical Research reported on IVF births between 1986 and 1990 (FIVNAT, 1995). They looked at 7,024 clinical pregnancies resulting in 5,371 births, finding a higher than average rate of multiple births and increased premature birth. The perinatal mortality rate was significantly higher for multiple pregnancies. The authors concluded that prematurity, morbidity and perinatal mortality are more frequent in ART than in natural conception and that multiple pregnancy is not the only explanation for this finding.

A study from Sweden assessed the entire population of IVF babies born over a 13 year period, between 1982 and 1995 (Bergh, Ericson, Hillensjö et al., 1999). The authors compared the health of 5,856 IVF babies with over 1.5 million naturally conceived babies in the general population. Twenty-seven percent of deliveries were multiple births (23.9% twins, 2.8% triplets and 0.2% quadruplets). The IVF children were more likely to be premature births (including singletons) and had a slightly increased rate of neonatal mortality. Rates of congenital malformation (excluding «minor» malformations) approximated that in the general population. Anencephaly, hydrocephaly and atresia of the esophagus were more common among IVF infants than controls. The authors attributed the increased risk of medical complications at delivery and birth defects to the five year average age difference in IVF mothers, their lower parity and the 27% rate of multiple pregnancy in the IVF group. In a related study by Wennerholm et al. using the same birth registry information the authors found a rate of 7.9% of congenital malformations in 1,139 infants conceived with ICSI/IVF (Wennerholm, Bergh, Hamberger et al., 2000).

The health of IVF children was evaluated by several other European countries. Birth registries in Belgium, Denmark, Finland and the Netherlands tracked large numbers of IVF and naturally conceived children (Bonduelle, Liebaers, Deketelaere et al., 2002; Westergaard, Johanson, Erb, & Anderson, 1999; Koivurova, Hartikainen, Gissler et al., 2002; Koudstaal, Braat, Bruinse et al., 2000; Anthony, Buitendijk, Dorrepaal et al., 2002). In general, IVF pregnancies had a 25% to 30% multiple pregnancy rate. When compared to naturally conceived controls, IVF infants tended to weigh less and be delivered earlier, but this effect disappeared when a control group was matched to the IVF group on maternal age, parity and plurality of pregnancy.

There is no central IVF/ART birth registry in the United States, so the data regarding the health of ART children is limited. The American Society for Reproductive Medicine and its Society for Assisted Reproductive Technology Registry tracks procedure and pregnancy related ART data, but it does not include data on infants' health. In the most recent summary describing the data from the U.S. in 1999, there were 63,639 IVF cycles initiated and 51,149 transfers among 360 reporting programs. Of these there were 19,428 clinical pregnancies (38% per transfer) and 16,175 deliveries reported. There was a 16.7% pregnancy loss rate. Sixty-two percent of the deliveries were singletons, 32% were twins, 4.7% were triplets and 0.2% were higher order multiples (SART & ASRM, 2002).

In a highly publicized study, Hansen et al. investigated the incidence of birth defects after ICSI and IVF in a sample of Australian infants (Hansen, Kurinczuk, Bower, & Webb, 2002). Using data from three birth registries, they evaluated the rate of birth defects in infants born via ART from 1993 to 1997. The sample included 301 infants conceived with ICSI, 837 with IVF and 4,000 naturally conceived. Mothers of the ART infants were older, less likely to have a previous child and more likely to be white and married.

ART infants were more likely to be born via caesarian section and to have a preterm birth and low birth weight. The rates of birth defects for the groups were as follows: 8.6% ICSI ($N = 26$), 9.0% IVF ($N = 75$) and 4.2% naturally conceived ($N = 168$). There were no significant differences in rates of birth defects across clinics. The results were similar and remained significant when only singletons were considered, when analyses were restricted to only singletons born at term and when the analyses were adjusted for maternal age and parity. When pregnancies that were terminated because of fetal abnormalities were included, the rates of major birth defects increased to 8.6% in the ICSI group, 9.4% in the IVF group and 4.5% in the naturally conceived group. The authors discussed possible causes for these findings: the advanced maternal age of ART mothers, the underlying cause of the infertility, the medications used during ovulation induction or to maintain the pregnancy and factors associated with the procedures themselves, such as freezing and thawing of embryos or delayed fertilization of the oocyte.

For the most part, conclusions drawn from these data indicate that IVF/ART children are healthy and thriving. When there are problems, they are generally associated with prematurity and low birth weight, usually the result of multiple embryos transferred, resulting in multiple births, lower later parity among the birth mothers and older age of mothers.

Studies of psychosocial health of ART children

The psychological and social adaptation of children conceived through ART has been considered by researchers around the world (McMahon, Ungerer, Tennant et al., 1997; Gibson, Ungerer, Leslie et al., 1998; Greenfeld & Klock, 1998; Klock & Greenfeld, 2000; Mushin, Barreda-Hanson, & Spensley, 1986). Studies of pregnancy and early infancy comparing IVF and naturally conceived infants have been reviewed

by Hahn (Hahn, 2001) and Van Balen (Van Balen, 1998). Most of these studies have used small samples and self-report measures of infant temperament.

In Australia, Gibson et al. (1998) compared the development, behavior and temperament of 65 IVF singletons with a matched group of 63 naturally conceived controls at 1 years of age. A strong point of this study is that the researcher administered the Bayley scales of infant development to subjects instead of relying on parental self-report data about their infants. The investigators also used measures of receptive and expressive language, social development and maternal assessment of behavioral problems. The results indicated that there were no significant differences between the IVF and control infants on any measures except the receptive language measure, in which IVF infants scored lower but still in the normal range. Additionally, a significantly higher percentage of IVF mothers rated their one-year-olds as "behaviorally difficult" than controls' mothers (35% versus 16% respectively). The authors conclude that the differences in maternal perception of infant behavior may be an extension of IVF mothers' lower level of self-efficacy in caring for their infants at 4 months postpartum that was found by their colleagues in an early part of this study (McMahon, Ungerer, Tennant et al., 1997).

Colpin and Soenen studied a group of 27 IVF families and 23 matched families with naturally conceived children in the Netherlands at 9 years of age (Colpin & Soenen, 2002). Parenting behavior, parenting stress and the child's psychological development were assessed by parent questionnaires and teachers' behavioral ratings were obtained for the majority of children. Parents were also asked if they had informed their children of their IVF origin. Results indicated that parenting behavior and parenting stress scores did not differ between groups. All the child behavior measures were in the normal range for both groups. Twenty-six percent of the IVF

parents had informed their children about their IVF origin, 59% said they intended to tell them, 11% did not know if they would tell them and one couple were certain they would not tell. Parents who had informed their child had done so during the ages of 4 and 8 years. Parenthetically, children who were informed had significantly higher problem behavior scores as reported by their mother and their father compared to IVF children who had not been informed. The scores were still in the normal range and are based on small numbers of children and parents. The authors conclude that, in general, there are very few behavioral and psychological differences between IVF and naturally conceived children at 9 years of age.

Hahn & DiPietro reported the results of a study of IVF and matched control families from Taiwan (Hahn & DiPietro, 2001). In this study they found that parents of IVF children were more similar than dissimilar to parents of naturally conceived children. There were some specific differences found, with IVF mothers reporting more feelings of protectiveness toward their children and greater separation anxiety as their child got older (study children were between the ages of 3 to 7). IVF mothers with one child reported less parenting stress than their control group counterparts and other mothers with more than one child.

Golombok has reported the outcome of the European study of IVF, DI, adopted and naturally conceived children in the U.K., Italy, Spain and the Netherlands (Golombok, Brewaeys, Cook et al., 1996; Golombok, Brewaeys, Giavazzi et al., 2002). In this longitudinal study the researchers followed 116 IVF families, 111 DI families, 115 adoptive families and 120 families with naturally conceived children. Children with birth defects or who were the product of a multiple pregnancy were excluded. The authors assessed parental and marital adjustment, individual anxiety and depressive symptomatology. Interview data ascertained the quality of parenting and observational ratings of the mother - child

interaction in the home. The Parenting Stress Index was also administered. Children's emotions, behavior and relationships were also assessed by the child's mother and teacher. Results indicated lower anxiety and depression levels in mothers of assisted reproduction children compared to mothers of naturally conceived children. ART mothers were also assessed as providing significantly higher levels of warmth and emotional involvement to their children than the naturally conceiving mothers. The ART group and adoption groups were similar on these two dimensions of parenting. No significant differences were found in the children's behavior or emotional problems, nor in the children's feelings toward their mother or father.

In the second phase of this study 102 IVF, 94 DI, 102 adoptive and 102 families with naturally conceived children were assessed from the original sample (Anthony, Buitendijk, Dorrepaal et al., 2002). Measures of parental depression, anxiety and parental stress were included, as well as interviews with both the parents and the child, to ascertain relationship quality. The child's behavior was assessed by parent and teacher rating scales. Results indicated no differences in parental depression, anxiety or marital satisfaction. ART mothers reported greater enjoyment of motherhood than naturally conceiving mothers. ART mothers also had higher ratings of emotional involvement with their children than natural or adoptive mothers, although analyses also revealed that ART mothers were also more likely to be rated overconcerned or overprotective of their child. ART fathers were rated as displaying more warmth toward their child than the natural conception or adoptive fathers. They also showed greater enjoyment of fatherhood than the natural conception fathers. For mothers there were no significant differences between groups in level of supervision of their children or disciplinary indulgence.

The literature suggests that the psychosocial

development of ART children is generally good and there do not appear to exist great differences in behavior and temperament between IVF and naturally conceived singletons. It also indicates that parenting behavior and parenting stress do not differ significantly between IVF and naturally conceiving parents.

Psychological issues in ART families

While studies show that there are no important differences between ART and naturally conceived children, there are several psychological concerns unique to ART families. These include the possible psychological sequelae of infertility and its impact on the transition to parenthood, the common emotional aspects of secondary infertility and the social, psychological and financial impact of having multiples.

The impact of infertility

While not necessarily permanent or even long lasting, infertility may play an important role in the experience for couples, particularly when the journey has been long and accompanied by years of failed treatment and/or pregnancy loss. The transition to parenthood may be complicated by either parents' inability to leave their «infertile selves behind» (Burns, 1999) and by residual feelings commonly associated with infertility, such as anxiety, depression, lack of self-confidence and low self-esteem. For some formerly infertile women, this can lead to psychosocial distress during pregnancy. This may include fears of pregnancy loss, anxiety about the ambivalence normally experienced during pregnancy, difficulty making an emotional attachment to the pregnancy and cognitive dissonance – the gap between the long imagined infant and the real one (Bernstein, 1990).

On the positive side, couples who have been

through long and difficult years of infertility may be protected from experiencing the normal decreases in marital satisfaction that most couples with new babies experience, because they are typically older, better educated and less likely to define themselves solely in romantic terms (Burns, 1999). Additionally, they may feel closer as a result of their long infertility experience, may find that they turn to each other more around parenting issues and, in general, are mutually supportive. Though they may feel incompetent at times (like most new parents), they may feel especially comfortable turning to each other for help (Burns, 1999).

Secondary infertility

While more common than primary infertility, secondary infertility is rarely addressed. In fact, we know very little about the impact on couples who, having easily conceived before, now find themselves unable to conceive again. They live in a world where they are neither childless nor able to conceive again. Since they had a baby before, they resist the idea that something may be wrong and often delay seeking treatment. Consequently, when they do finally enter the world of infertility and ART treatment, they are often full of regret for not seeking treatment earlier. They may feel guilty for not being able to provide their child with a sibling. Additionally, we know very little about what happens psychologically to children who were easily conceived but now experience their parents' pain and anguish in trying to «get them a sibling».

Those couples who conceived their first child with difficulty as infertility patients may find themselves disappointed that they were not «cured» by pregnancy. Having to go through the experience again may stir up old feelings of inferiority, low self-esteem, defectiveness, fear of pregnancy loss, anxiety and depression. The emotional stress of ART may reappear with the same intensity as it did during the earlier

treatment. In both cases, those going through secondary infertility often experience guilt at not being able to produce a sibling for their child. This is made more difficult when their child asks for a sibling, as parents at times have difficulty separating their own needs for a second child from their child's need to have a sibling. It is also especially challenging to experience infertility treatment while juggling the demands of parenthood. Boundary issues may emerge about what and when or if the child should know about his parents' treatment (Simons, 1995).

Raising multiples

While many parents of multiples feel overjoyed and «especially blessed» to have an already made family after so many years of trying, few are prepared for the emotional and financial stresses that bringing home multiples really entails (Burns, 1999). Parents of multiples often find themselves feeling trapped, isolated and exhausted by the extraordinary demands of caring for more than one infant at a time. For example, if the multiples are premature and have required an extended stay in the hospital, we know little about how this affects parents' capacity to bond to the infants. Mothers may find some of the expected warm and caring feelings are delayed when children spend a substantial period of perinatal time separated from them (Klock, 2001).

Couples entering ART treatment programs with long histories of infertility and childlessness may welcome the idea of having more than one baby at a time. They may be concerned about the financial burden multiples may bring, but totally unaware of the medical risks associated with multiple pregnancy. Childless couples may have an especially difficult time imagining the practical and emotional difficulties of caring for more than one infant at a time.

Considerations for mental health counsellors

In many IVF centers (among those fortunate enough to have a mental health professional) the counsellor may be afforded only one pre-treatment session. The infertile couple, nervous and anxious about the treatment itself and perhaps concerned about «looking good» to the counsellor, is focused first and foremost on the cycle itself and whether or not it is going to work. Given that they may have difficulty seeing themselves as possibly entering a successful cycle and actually getting pregnant, it may be particularly difficult for them at this moment to imagine themselves entering the world of parenthood! Hence, a discussion of children conceived through these treatments during this initial interview may strike them as untimely and premature. These issues may have to yield precedence to more pressing issues, such as how they will cope with the possibility that the treatment may not be successful, that the treatment may be successful and produce multiples and that they also need to think about possible embryo distribution, even the possibility of pregnancy reduction.

On the other hand, even a brief discussion of parenting after infertility can be very reassuring. The fact that this technology can actually produce healthy children, that there are many in the world and that the first is now older than 25 is in itself very reassuring and may be news to couples embarking on this journey. An exploration of the couples' families, particularly their degree of support or non support for the couple during the anguish of infertility, is also a useful way of introducing the topic of how the couples see themselves as members of a family and of how they are likely to approach having their own family. While not intending to diminish the pain and suffering of the infertility, the counsellor guides the couple into actually beginning to think that they may well be successful and need to begin thinking about parenting.

Resource material around issues of ART, such as infertility support, pregnancy loss, secondary infertility, parenting after infertility and special support for families raising multiples, is an important addition to the support and counsel provided by mental health professionals working in ART.

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