
Loss in Higher Multiple Pregnancy and Multifetal Pregnancy Reduction

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From early pregnancy into childhood, higher multiples have much higher rates of mortality, whether from spontaneous abortion, the 'vanishing twin' syndrome, fetal or infant death. Many parents must cope with the death of one baby whilst the siblings remain critically ill or later become disabled and yet there grief is often underestimated. Little is known about the long term feelings of parents who choose to have a multifetal pregnancy reduction (MFPR). Most say they made the right decision but also that there was insufficient respect for their loss. They are often anxious about what, if anything, to tell the survivors and how they might react. Long term follow-up studies of the children as well as the parents are needed. Meanwhile parents who chose to have a MFPR must be given more information and ongoing support.

Much of what has been said by Swanson et al. (2002) and Kollantai (2002) of the problems and needs of bereaved parents of twins also, of course, applies to parents of higher multiple birth children. However there are some additional considerations, especially in relation to multifetal pregnancy reduction.

First many of these babies will have been conceived after many years of anxiety, uncertainty and often distressing forms of treatment for infertility. Although there is no country that officially records the form of conception of multiple pregnancies, the disproportionately rapid rise in higher multiple births in all developed countries suggests that at least two thirds of triplets now arise from treatment for infertility and, amongst the higher multiple births, an even greater proportion.

Not only will these babies be seen as particularly precious, but the parents may have started to relate to them very early in the pregnancy. Many triplet pregnancies will be diagnosed, and seen by the parents on ultrasound scan, as early as the fifth or sixth week.

Loss of the Whole Pregnancy

About 20% of triplet pregnancies are likely to end in miscarriages before 24 weeks (Lipitz et al., 1994). In another substantial proportion the pregnancy will end with the mother delivering three, four or more live frail, preterm babies, only to see them all die soon after birth or die one by one over many agonising months in neonatal intensive care.

If the pregnancy had resulted from treatment for infertility, couples may be angry to have been prescribed a treatment that resulted in a higher order pregnancy and therefore blame their infertility specialist for their babies' prematurity and

death. Couples should always be offered the opportunity to see their specialist as soon as they wish after the death(s). Despite the loss some couples will continue to request the transfer of three or more embryos (Sullivan Collopy, 2002) and thereby risk another tragedy. They may well need to be encouraged to delay further treatment until they have sufficiently recovered from their bereavement.

Loss of One Baby

When none of the babies survive the parents' tragic loss will at least be fully appreciated by others. A couple who lose one or two of their higher multiple births but have at least one surviving child often receive remarkably little sympathy even though the loss of any child is deeply felt and the repercussions of the loss of one triplet may be as serious as the loss of a single-born child and often more complex.

Vanishing Fetus

Many more higher multiples are conceived than are delivered as triplet sets. In a study of 10,000 first trimester ultrasound scans Pharoah and colleagues (2001) found 10 pregnancies with three gestational sacs. Two of these aborted and two were reduced to a twin pregnancy by a vanishing fetus. There may have been further three embryo pregnancies which had already 'vanished' before the scan.

Before the era of ultrasound scanning these higher multiple conceptions would rarely have been recognised. Some obstetricians are hesitant to tell couples of their multiple pregnancy until the end of the first trimester because of the high frequency of an early loss. However, many parents say they would prefer to be told that there is more than one fetus from the outset even though they must also be warned of the substantial risk of losing one or more of them. Indeed some parents argue that they have a right to this knowledge not least because of the increased chances of conceiving multiples again in future pregnancies.

The effect on the parents of these early losses varies greatly. For some there is a sense of relief if they end up with one or two healthy babies instead of triplets. Others may be ambivalent or have only transitory regrets. For those considering a MFPR, a spontaneous reduction of one

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fetus can solve a painful dilemma. Some couples however may be profoundly affected. It is essential that their loss is respected, and they may well require ongoing support to cope with a bereavement that is rarely sufficiently appreciated by other people. Furthermore, the reaction of the two parents may differ and this may be a source of tension or conflict between them.

Perinatal Death

Compared to singletons, the mean gestation for triplets is about 6 weeks (and quads 8 weeks) less and their mean birthweight 1800g and 1400g respectively. It is therefore not surprising that their perinatal mortality is about nine times greater than singletons.

The experience of a parent watching three babies precariously holding on to life, with all the hour by hour crises and hopes involved, can be emotionally overwhelming. Most triplets need to be nursed on a neonatal intensive care unit and seemingly minor incidents can have stressful repercussions for the parents. For example it is essential that the babies' incubators are readily distinguishable at a distance and that parents are always informed of any repositioning of cots/incubators before they enter the neonatal unit.

It is not unusual for sick preterm triplets to be transferred from their hospital of delivery to tertiary care neonatal units (Macfarlane et al., 1990). The mother may be unfit to travel with them. Furthermore, the triplets themselves may be separated by many miles when no single hospital can provide three intensive care cots at the time they are needed. This can become an emotional nightmare for both parents and a logistic one for the father as he tries to keep in touch with his partner and each baby. In such cases photographs should be taken and regular updating of all staff on the condition of all members of the family is vital. Staff often need reminding that there are other babies (whether alive or dead).

Each infant of one set of extremely preterm triplets was placed over 100 miles from the other, and from their mother. The father struggled to visit all four and finally had to collect the death certificates from three neonatal units. The mother never saw her babies.

In such cases, it is more difficult to organise and collect mementos of all the babies and if they are geographically separated impossible to get a photograph of the three together. Their presence or absence can become important in the recovery from grief in the longer term. Focussing on this issue can be well rewarded in later months and years. Sketches and paintings of the triplets drawn from individual photographs or from the parents' description can provide a picture which parents will treasure (Cuff, 2002). In the case of miscarriages (see colour page 248), severe congenital anomaly or disfigurement (as in fetuses who have died some weeks before delivery), parents are often more comfortable showing such a picture to their friends, rather than a photograph.

However parents should not be discouraged from having photographs taken if they ask for them. I have seen a photograph of triplets of whom one was a fetus papyraceus

(sensitively dressed) by the side of two live baby siblings. This has given continuing comfort to the parents.

Following the death of one baby, parents should be helped to consider whether they wish to postpone the burial or cremation until the fate of the other (often critically ill) babies becomes apparent.

Many of these parents who lose a baby in the newborn period postpone their mourning for months, even years. They can be so preoccupied with the remaining babies, especially if they are critically ill and suffering from the same problems (e.g., complications of prematurity) that they are unable to create time and space for their sorrow.

Some couples have to cope with their grief over the death of one child (or more) while at the same time having to face the daily difficulties and emotional strain of caring for a disabled child. After 12 years of infertility one couple conceived quads following GIFT. The babies were delivered at 26 weeks gestation. One baby died after six days, the second died after six months, having never left hospital. The third was severely disabled and the fourth proved to be a bright child but very small. The strain on the family was inevitably enormous and, after four years, the marriage broke down.

A problem that arises with surviving higher multiple birth children, but not with a single surviving twin, is that of the distress caused to the parents by inaccurate labelling of the children. Many parents are upset if their two surviving triplets are called 'twins' or the surviving quadruplets called 'triplets'. For some this can become an obsession. I have seen such couples either refuse to meet people or constantly aggressively correct the speaker to the embarrassment of everyone. I have had to help a number of parents come to terms with this problem which is understandable but in practice virtually insoluble

Multifetal Pregnancy Reduction (MFPR)

As the number of higher multiple pregnancies has escalated, so have the number of couples who decide that they should maximise the chances of having healthy babies by reducing the number of fetuses — a multifetal pregnancy reduction. (The term selective fetocide should be limited to a pregnancy where one — or more — of the fetuses is being reduced because of an anomaly). Most pregnancies are reduced to two and a few to three.

Although both the mortality and morbidity of twins is significantly higher than that of singletons it is rare for pregnancies to be reduced to one fetus except in high risk cases such as severe maternal disease or a previous history of recurrent preterm delivery or miscarriage.

Since the mid-1980s this option has been available to couples in an increasing number of countries although the procedure remains illegal in some such as Japan and Germany.

Most agree that 11 to 13 weeks gestation is the preferable time for performing the procedure as the risk of a spontaneous reduction is by then low. However some obstetricians prefer to do it as early as seven weeks so that an aspiration can be performed rather than a cardio toxic injection. They also suggest that a procedure performed earlier in the pregnancy may be easier for the couple to

accept. However this does mean that there is less time to come to a decision (Bergh et al., 1999).

Much experience has been gained in particular in Israel and the US where there is no limit on the number of embryos that may be transferred and higher multiple pregnancies are in consequence even more common. Nevertheless the use of ovulation inducing drugs can also cause high multiple pregnancies so, even with restrictions on embryo transfer in IVF, countries may have large numbers of higher multiple pregnancies.

A recent international survey (Evans et al., 2001) of 15 years experience at 11 centres and a total of 3513 cases showed that with increasing experience there has been a considerable improvement in the outcomes following the procedure with decreases in rates of pregnancy loss and of extreme prematurity. The proportion of cases with starting numbers of five or more during the 15 years diminished from 23.4% to 12.2% and the outcome correlated strongly with starting and finishing numbers. Those who started with triplets and reduced to twins did the best.

This survey showed that that the reduction of quads as well as triplets to twins now produces outcomes as good as those for unreduced twin gestations. It has been argued that in countries without a legal limit to the number of embryos transferred in IVF the option of a MFPR removes the physician's incentive to transfer fewer embryos. Most however would agree that MFPR should be viewed as a response to an unforeseen and unavoidable contingency and not a routinely accepted remedy for a iatrogenically created problem.

A few sets of quintuplets and sextuplets, as well as many sets of triplets and quadruplets, have been born healthy and lived happily. Nevertheless, the medical risk for quads and more are such that consideration of an MFPR is certainly justified on medical grounds. Opinions in regard to the medical justification for the reduction of a triplet pregnancy vary amongst obstetricians (Leondires et al., 2000) depending on their personal experience, the standard of neonatal care available to them and on the maternal factors such as age and past obstetric history.

An increasing number of obstetricians decline to reduce to triplets on medical grounds. This puts an added burden of responsibility on to the couple who want their triplet pregnancy reduced because of the financial, practical or emotional stress that they feel they would face. Some obstetricians still feel reduction of triplets is medically justified on the grounds of reducing prematurity and low birthweight (Lipitz et al., 1996; Yaron et al., 1999). Indeed some units propose MFR routinely to all couples with a triplet pregnancy and Nantemoz and colleagues (1991) reported that couples found it emotionally easier if they felt the responsibility for the decision was being carried by the physician.

Many papers on the techniques and the medical outcome for the surviving babies have been published but there is relatively little information available on the psychological outcome for the parents and none on the impact on the children themselves.

The Decision

Some couples of course will reject the idea of MFPR on moral, religious or other grounds however great the risks to the mother or the babies. One couple said: "To get rid of it or selectively abort or whatever is murder. It's the taking of a human life. That's God's job. He's the one who decides who's going to be born and who isn't" (quoted in Elster, 2000). Couples have chosen to continue with octuplet pregnancies only to miscarry or to see their extremely premature infants stillborn or die one after the other over the first hours and days of life.

Many couples expecting higher multiples will share some of these misgivings but recognise all the risks and problems involved and then judge a fetal reduction to be the least bad option. Fetal reduction is however rarely seen as an easy or uncontroversial solution and it carries its own risk of both medical and emotional complications (Bryan and Higgins, 1995).

The balance of risks and advantages will be seen differently by each couple but for all there will be a sense of responsibility and much anxiety. There is no obvious or comfortable answer to the dilemmas involved and the short time available between the diagnosis and the optimal time for the procedure often adds to the stress.

For many couples the overriding aim will be the safe birth of the one healthy child they originally sought. Their next biggest concern will be the health and welfare of any of the surviving children from this multiple pregnancy and of any other children in the family. Parents' concern about the physical, emotional and financial demands will vary greatly between (and within) couples and will not necessarily correlate with their socioeconomic status (Garel et al., 1997).

Many couples undergoing treatment for infertility complain not only of the lack of information (Kanhai et al., 1994) on the risks and implications of a multiple pregnancy but that MFPR had not even been mentioned. Indeed some had never even heard of the procedure until it was starkly proposed as an option for them. Others had difficulty in finding appropriate information and counselling whilst trying to make their decision.

When the question has to arise some units have structured protocols for counselling couples. These may not however allow the time that the couples feel they need to come to a decision especially if the counsellor is a busy physician. Furthermore, if this is the doctor who would go on to perform the reduction, couples may feel under pressure to follow his or her advice.

Bergh and colleagues (1999) found that most couples had little difficulty on agreeing on a decision, one way or the other. This is not always the case. One partner may have deep religious objections. One, often the mother, may be distressed at the thought of disposing of a potential baby of hers whereas the father may be equally distressed by the idea of having a disabled child. Both partners will need to weigh carefully and sensitively the arguments on both sides. It is sometimes only with the help of a counsellor that they will come to understand each other's individual views and feelings. What follows are quotations from the letters of one couple illustrating the evolution of feelings as they struggle to reach their painful decision:

Mother: This was the start of a desperate five week period of agonising over our predicament. I felt we were completely at odds. Throughout the stresses and the emotional rollercoaster of undergoing IVF treatment, we had been very close. Now I felt we were struggling.

Mother: It became clear that P and my views on what we should do were at opposite ends of the spectrum. P is practical, rational and realistic. I was carrying these three babies and still wanted to imagine it could work out all right and somehow be able to cope.

Mother: It seemed to us to be a completely 'no-win' situation. We felt quite unable to make a decision either way. The only thing which had improved was that we now felt the same about the situation — i.e. utterly undecided and unhappy — but at least we were on the same wave length.

At 11 weeks the couple decided to undergo an MFPR but at the pre-operative scan they found that one fetus had reduced spontaneously

Father: Seeing healthy, whole babies on the screen when we were to make a decision about a fetal reduction brought home to me the enormity of what we would be doing — taking the life of one of our babies. I think we would have found it very difficult to live with the thought that we had deprived his brother or sister of the same right to life.

Even where the couple decide to undergo a reduction, it is important to identify and clarify beforehand the emotional issues that have been stirred up. They may well, for example, be distressed by the seemingly arbitrary choice as to which fetus should live and which should die. Moreover this arbitrariness will actually be real in many cases and will need talking through.

Even though the fetus selection is usually made on the grounds of technical accessibility, parents may feel that they are playing God in sacrificing one baby in preference over another. As one mother said, "How could you say I'll kill him but not her?"

Although the surviving fetus should suffer no physical ill effects, the thought of a live baby lying for many weeks by the side of his dead twin can also be very distressing. Moreover, when no fetus has actually been expelled, the natural tendency to deny and forget the sad reality becomes much easier and feelings of loss are postponed. On the other hand some may be able to think of the fetus "just as a bunch of cells" as one mother described it and not yet fully human.

Procedure

The procedure itself is usually remembered as very stressful and, for many, frightening (Bergh et al., 1999; McKinney et al., 1995; Schreiner-Engel et al., 1999). Some complain of pain during the procedure but for most the emotional pain and stress is the greatest concern (McKinney et al., 1995; Schreiner-Engel et al., 1999). Sometimes the procedure fails on the first attempt, which has to be repeated and so adds disproportionate anxiety sometimes lasting throughout the pregnancy (Bergh et al., 1999; Sullivan Collopy, 2002).

Later

Some parents will feel a lasting grief and guilt over the death of one or more potentially healthy children. Nevertheless it appears that the great majority who do proceed with a reduction feel afterwards that they had made the right decision (Bergh et al., 1999; Garel et al., 1997). The happiness of getting the children usually overshadows the problem of the reduction (Bergh et al., 1999)

Sometimes there will be a miscarriage or death of one of the remaining fetuses following the procedure. Inevitably the grief will then be compounded by feelings of personal responsibility and guilt. Couples may then deeply regret their decision to accept an MFPR.

There have been a number of follow up studies reported on mothers following an MFPR (Garel et al., 1997; Kanhai et al., 1994; McKinney et al., 1995, 1996; Schreiner-Engel, 1999). All found that many mothers suffered emotionally with guilt and grief initially but that few had serious problems after the first year. In general there appears to be no evidence so far of long term psychiatric risks associated with MFPR.

Garel and colleagues (1997) compared 18 families who had reduced higher multiple pregnancies to twins and 11 with non reduced triplets. When the children were 12 months old, one third of mothers reported persistent depressive symptoms related to the reduction. By two years, these had disappeared for all but two and compared with the triplet group the psychological health and relationship with the children was better in the reduced group. However these findings must be viewed with caution as nearly half the mothers in the MFPR group declined to participate in the study. My own experience has been that of a much lower response rate to invitations to follow up appointments in MFPR mothers than those, for example, who have either suffered a perinatal bereavement or who have surviving triplets. These latter two groups usually welcome the chance to tell their story. Whether the low response rate amongst MFPR mothers is due to the ongoing wish for secrecy or to feelings of guilt can only be speculated. In one small study six of 11 mothers had only told close friends about their MFPR, six had told everyone and one had not told anyone at all (Bergh et al., 1999)

The Children

In the short term, at least, the surviving children appear to be at no greater risk than others of physical or intellectual problems.

A key question is whether the parents should ever tell the surviving children about the fetal reduction or keep it as a life-long secret. There have been no studies reported of couples intentions on this issue, let alone what they did in practice and what the results were. As the eldest survivors from this procedure must now be in their teens, it would be helpful to know more.

If couples decide never to tell their children it is virtually essential that neither a neighbour nor any other member of the family is ever told about it. A significant cost of the parents' resolve as to secrecy is therefore that they are discouraged from consulting or seeking comfort

from even their very closest friends. This inevitably makes it harder for them to find the support they may need.

Several highly sensitive questions are of course involved. Any of the survivors could feel their own survival was achieved at the expense of a sibling and hence carry lasting guilt over it. They could also see their parents as 'murderers'. They could reckon their own existence to be essentially arbitrary and their own individual value as therefore impaired or even undermined. There is as yet no report of a study on the responses of the surviving children.

Support

Support and counselling for those considering MFPR should be part of the continuum of care of all couples embarking on any form of treatment for infertility that involves ovulation induction or multiple embryo transfer. Counselling should be readily available to both partners both together and individually before and after the MFPR and for as long as they wish. Some may return for help many years later, not least to discuss their surviving children.

Approaches and practices differ between units and many couples feel they have not received the comprehensive support they needed. Members of the team may have lacked knowledge, sensitivity or both. Some couples have, for instance, found that they have had to explain the nature of MFPR to their family doctor. Ill prepared ultrasonographers have been surprised to 'discover' a dead fetus (Sullivan Collopy, 2002).

Many couples find it helpful to talk to someone other than the practitioner who will carry out the procedure. Some units follow the good practice of offering a counsellor or social worker who becomes the key worker to that couple, available throughout to discuss any issues that may arise.

Britt and colleagues (2001) have described a structured intervention programme which aims to lower parental anxiety and increase bonding to the pregnancy after the reduction procedure. During the procedure couples are encouraged to refocus their attention on the surviving 'twins' or singleton and the normal pregnancy they can now expect.

Others would feel uncomfortable with this approach which tends to ignore or deny the grief and the very existence of some of the fetuses. They would argue that it is only by consciously relinquishing the fetus(es), that the parents can then move on to relate satisfactorily to the surviving babies. One mother actually needed explicitly to say 'goodbye' and to say she was sorry (Britt et al., 2001; Sullivan Collopy, 2002). Some have requested a photograph of the ultrasound scan, believing that all the fetuses should be remembered and respected.

Some couples, of course, will prefer that others 'forget' what has happened and will not wish any reference to be made to it (Bergh et al., 1999). Particular sensitivity is needed by the carers in helping such couples, especially if they have chosen not to disclose anything to their relatives and friends.

Many couples will feel a profound bereavement, at least initially, and will rightly expect this to be respected. One of the main obstacles to providing optimal support to couples is that we, the professional carers, are also struggling not

only with our ignorance but also with our own confused and negative feelings.

In an effort to help resolve some of these feelings and to make positive recommendations, the Multiple Births Foundation (MBF) invited a group of interested professionals including infertility specialists, psychotherapists and counsellors to discuss the issues surrounding MFPR. All the issues described in this paper were discussed but all felt their previous experience poorly prepared them for coping with the subject and most felt distinctly uncomfortable about it. The main outcome was the realisation of how little we know yet about this process and how vital it is that more follow up studies are carried out with the surviving children as well as their parents. Only then can evidence based advice and support be offered to parents through what is bound to be a difficult time and for as long as they need it.

The MBF publishes a leaflet (MBF, 2000) for couples faced with the option of fetal reduction and can also give more individual advice about dilemmas that will inevitably be painful and to which there cannot be a wholly satisfactory resolution.

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