It may be appropriate to have a specific clinic for young mothers and/or a group where the young women could share their expectations and fears and meet other people in a similar situation. Much might be gained from providing an opportunity for antenatal and postnatal young women to meet as they will be able to relate to each other and share experiences (MacKeith *et al.* 1991).

Another way in which young women might raise their self-esteem and feel more in control could be to involve them as much as possible in their own care. For example, they could be taught how to test their own urine, take each other's blood pressure and listen to each other's babies' heartbeats. This can help to demystify antenatal care and stimulate useful discussion.

In labour too, it is important to remember to involve young women in their care. As it is for many older women, it might be easier for a young woman to submit passively to what happens. Her expectations may not appear to be great, but she will have hopes and fears of her own. Labour plans can be useful but may need to be updated as the pregnancy develops and expectations change. Discovering what those fears and hopes are, sharing information fully and encouraging her to decide what would be best for her are the challenges. Where major or minor intervention is needed, a young woman can still be involved in the making of decisions about her care. Having some feeling of control and an understanding of what is happening can help her to come to terms with her experiences at a later date.

How can midwives nurture a young mother's confidence in herself and her new role, that of caring for her child? There must be a balance – all new mothers need to be nurtured, as illustrated by the role of the 'doula' (Raphael 1973, Odent 1992). With a young woman, particularly a very young one, it can be all too easy for a midwife to be overwhelming, to be overprotective, to take over, to make all her decisions for her.

Are we too prescriptive in the way things are done, for example in the way in which we demonstrate bathing a baby? Do we do too much for the mother or make decisions for her? She may have cared for small babies many times before, she might already have a wealth of experience, and if so we need to acknowledge her skills and build on them. How do we assess each mother's needs for support, encouragement and information? Once she is home, how do we ensure that she has appropriate support or adequate living conditions?

Midwives can be flexible in the way in which they offer their service. We cannot change people's lives, but we can ask ourselves whether there are any ways in which we can help. What benefits is this mother entitled to? Could she qualify for better housing? Where can she meet other young mothers? Midwives can introduce women to each other and therefore help to reduce the isolation that can be a major health hazard (MacKeith *et al.* 1991). Midwives should be a great source of knowledge about other agen-

cies available, but need to have a clear understanding of what each service can offer and ensure that referrals are appropriate and effective.

SUPPORT FOR MIDWIVES

Working with young mothers can be quite demanding as they may have special needs apart from those common to all mothers. In any situation where we decide to change our way of practice, there is a challenge, but this can also be frustrating and sometimes frightening. To help us to develop our practice, we all need encouragement and support. Before embarking on changes, it can be helpful actively to seek out support. This might come from a variety of sources. We need to find people who have an understanding of what we are trying to do, as well as others who may have experience in working within this field. We may find the support we need from managers and midwifery colleagues, but it may be necessary to go further afield, for example to youth workers, teachers or community workers. Appropriate support is extremely important (MacKeith *et al.* 1991).

EVALUATION

Evaluating our work is essential. It enables us to learn continually and to modify and improve our practice. Evaluation also provides information about the service we are giving and how effective it is in achieving our goals. Managers need this information in order to give us support for what we are doing. In order to evaluate, we need to be very clear about what we hope to achieve. As discussed earlier, our aims include not only healthy mothers and babies, but also other goals, such as mothers who feel confident in their new role. Quantitive evaluation, for example figures on birthweight and mortality, is relatively straightforward compared with qualitative evaluation in which we measure the less tangible outcomes. Raising self-esteem and alleviating isolation, for example, are difficult to measure, but they are important achievements and can have lasting effects on the long-term health of the family. As midwives, it is important that we ensure that these achievements are given a high profile. Therefore we need to find the means to measure these outcomes so that we can convey their importance to managers and planners.

SUMMARY

The majority of teenage mothers are 18–19-year-olds and are from families with a tradition of early parenthood. Where young women's prospects are poor in terms of employment, they see little reason for deferring motherhood.

Evidence suggests that good sex education and a comprehensive family planning service are effective in reducing the teenage pregnancy rate. Contrary to popular belief, they have no effect on the average age at which young people become sexually active (Barth *et al.* 1992).

Research suggests that poverty rather than age is the main factor affecting poorer outcomes for young families (Butler *et al.* 1981; Makison 1985; Carlson *et al.* 1986).

Adolescence is a time of ambiguity, being an adult and a child at the same time. Being a mother causes further confusion for society, which on the one hand is shocked at the 'child' having a child, yet on the other is expecting adult and responsible behaviour.

Different ways of providing a midwifery service that meets the needs of young mothers include, for example, the importance of attitude and approach, as well as the provision of specialised clinics and groups. There are many ways in which midwives can involve mothers in their own care, and these can lead to a positive working partnership with young people.

Midwives themselves need to be supported, both in this type of work and when changing their practice. It is important to devise appropriate methods of evaluating our service in order to plan and improve services for young mothers. The majority of young mothers work very hard under difficult circumstances and become good mothers. As midwives, we can have considerable influence on this.

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CHAPTER NINE

Pregnancy following assisted conception

Mary Sidebotham

When a previously infertile couple realise their dream and a pregnancy is achieved, there is very little information available to them, or to the professionals caring for them, on how to cope with the mixed and varying emotions they may experience during the pregnancy. How will they adapt to parenthood? Will the transition from being infertile individuals to parents be difficult or smooth? How may they shed the identity of failure and learn to live with success?

The motivation to reproduce may be instinctive, reflecting a biological need to pass on one's genes (Winston 1987). The survival of the species depends on reproduction. With the introduction of reliable contraception and safe, legal abortion over the past 35 years, women have been granted a degree of control over the process. However, conception is not always as easy as it is expected to be.

There is great social and cultural pressure upon couples to conform and produce a child (Kozolanka 1989). Many individuals may see reproduction as a means of achieving adulthood and may desire a child to give them the chances in life that they never had themselves (Raphael-Leff 1991). Or they may regard the birth of a child as confirmation of their body's normal functioning ability and successful gender role fulfilment (Lasker & Borg 1989). Furthermore, according to Oakley (1986), children are seen as 'the inalienable property of women, symbolising achievement in a world where underachievement is the rule'.

Infertility affects about 1 in 6 of the population. The desire to bear children can be overwhelming, and the distress and grief experienced by couples who fail to conceive naturally can be devastating (Kon 1993). However, there is a wealth of information available for couples who wish to pursue their dream and have a child. Possible avenues for the couple to pursue are given below. When the couple are still at the stage of considering their options, they will find plenty of available information on the possible avenues, including:

- adoption (Toynbee 1985);
- surrogacy (Cotton & Winn 1985; Reid 1988);

- the use of donor gametes in a reproductive cycle (Snowden 1984);
- the *in vitro* fertilisation process itself (Lasker & Borg 1989; Klein 1989).

Because of the relative newness of this field of science, however, there has been very little work published on the subject of parenting *after* infertility, especially following the use of the modern reproductive technology that is currently available. While being based in practical experience, this chapter considers what relevant research there is. Midwives need to have an insight into the emotional pain felt by couples who face a diagnosis of subfertility and the effect that the treatment has upon the couple and their relationship. Midwives must also be aware that these experiences may have a profound effect on the couple's acceptance of the pregnancy and their eventual relationship with their child. The challenge is to know how best to help the couple when problems, either real or potential, are identified. A major part of the midwife's role involves sharing her knowledge and experience of the transition to motherhood. By working in partnership with the couple, she may be able to explain that the same worries and emotions are felt by many other new parents-to be.

INFERTILITY AND EMOTIONS

> Every month my future child bleeds to death, hope is driven painfully away from me because I don't want to let go, I want to hold on. Every month a little miscarriage, an abortion of my hopes. (Belk-Schmehle 1989)

This quotation vividly describes the pain of failed conception. Each month the arrival of the menses can signal a crushing sense of failure in the couple trying to conceive (Mahlstedt 1985). This can have a devastating effect upon their whole lives, altering relationships and personal perceptions, overshadowing everything else. The effect upon one or both partners can be so strong it may even lead to suicide (CIBA Foundation 1986).

When subfertility is diagnosed, the couple often go through a grieving process. All the reactions of shock, denial, anger, guilt, depression and resolution can be found in the literature (Edelmann & Connolly 1986). If investigation identifies one partner as being responsible for the problem, it can cause extreme depression, with a feeling of isolation and failure in that person (Hargreaves Pearson 1992). A loss of body image may be experienced and a sense of failure in the gender role. Men may suffer temporary impotence following diagnosis (Raphael-Leff 1991).

The diagnosis may cause a feeling of resentment and anger in the other partner, be it open or hidden, which may put an extreme strain upon the relationship. The sexual relationship may change as intercourse loses the loving element and becomes a monthly chore. Women are reported as

being more likely to exhibit anxieties and negative emotions (Ravel *et al.* 1987). The couple may feel an irrational level of guilt about their infertility, especially if they have had other sexual partners and have suffered from sexually transmitted diseases (Downie 1988). Many relationships are thrown into a state of turmoil and distress.

In the past, choices for such couples were very limited. They had either to resign themselves to remaining childless or to pursue the possibility of adopting a child. Now, with the advances being made in treatment, together with the ever-decreasing number of babies available for adoption, more and more couples are seeking treatment for their infertility (Toynbee 1985; Warnock 1992).

Today, medical science holds out hope, but what appears to be a wide-open avenue of possibilities to conceive narrows as each option fails. The effort becomes funnel shaped, focusing upon the last urgent option, be it *in vitro* fertilisation (IVF) or artificial insemination by donor (AID) (Raphael-Leff 1991). With new treatments, which often have high profile media coverage, becoming available almost annually, many couples believe that their infertility can be cured (Pappert 1989; Hodginkson 1992). They may see the fertility specialist as a last resort, with almost God-like powers to give them a child (Winkler 1989). The treatment programmes can be extremely stressful, even 'dehumanising' (Wood & Westmore 1984). Some couples feel that they have succumbed to social pressures to conform and have thereby been coerced into treatment, leaving no stone unturned in their quest for a child (Jones 1991).

Women feel that their bodies are being manipulated (Corea 1985), and many men dislike the thought of their child being born as a product of masturbation (Lasker & Borg 1989). Some men find it impossible to produce the sperm sample at the required time, further increasing the tensions between the couple (Jones 1991). In some cases, couples in this situation have been asked to make a choice between going ahead using donor sperm or abandoning the treatment programme, without being given the opportunity to discuss this fully (Lasker & Borg 1989).

Not all couples undergoing fertility treatment will conceive the longed-for baby. After IVF, the live birth rate per treatment cycle is around 12.5–13 per cent (12.7 per cent in 1992, according to the Human Fertilisation and Embryology Authority 1994 statistics). As the couples themselves will be aware that only a proportion of attempts at assisted conception are successful, they may have very mixed feelings about other couples on the programme. It is hard to wish the precious successes on others in the same position, No one wants to deny the existence of their own 'phantom baby' who is just waiting in the wings (Raphael-Leff 1991).

Maintaining confidentiality and economic security may also prove difficult for these couples because of the long periods away from work, the potential costs involved and the physical effects of the hormone treatments.

SUCCESSFUL FERTILISATION

After the intensive treatment and attention couples receive from their doctors during the investigation and treatment of infertility, many couples leave the specialist centres once a pregnancy has been confirmed. They then become clients at the local maternity hospital where their full history may not be known. This change may lead to their feeling abandoned as the health professionals with whom they now have contact may have no concept of the magnitude of the fertility problems with which the couple have coped and the stress which will have been caused by the treatment. The couple may feel unable to discuss their doubts and fears with these carers, who see only their success. They have achieved their dream, a viable pregnancy. They may feel (or be made to feel) that they should be grateful, whereas they may in fact be experiencing continued anxiety about the eventual outcome of the pregnancy.

Although these couples will have received professional counselling, as recommended by the Warnock Report (Department of Health 1984), this does not continue once the pregnancy has been confirmed and they have come back into the main system. Even if a need for counselling to continue is identified, the facility may not always be available locally, or it may not be available immediately – an appointment for 6 weeks hence is no help in the immediate present.

The midwife's role

The midwife is ideally placed to help her clients to accept their pregnancy and enjoy it, as well as to provide information and reassurance (Garner 1985; Denton 1996). In order to help the couple who have achieved a pregnancy following infertility treatment, she must be fully aware of the psychological impact of infertility and the emotional, physical and often financial stresses placed upon a relationship by infertility treatment.

Problems identified in the literature to date which are commonly experienced include those associated with what one author describes as 'the tentative pregnancy' (Katz Rothman 1988). The couples concerned have become used to failure, and after what may have been years of trying, they may find it hard to believe that the pregnancy is real and will continue successfully. Dunnington and Glazer (1991) suggest that they may use denial of pregnancy as emotional protection against further potential failure. Garner (1985) suggests that the fear of disappointment, heightened anxiety and denial of pregnancy could cause delayed parent–child attachment, along with a delay in preparing for the child and difficulty in re-integrating parental roles when the child is born.

The denial of pregnancy may delay the development of maternal identity, which Rubin (1984) believes begins during pregnancy. A woman who

fails to conceive changes her personal perception. She no longer sees herself as a healthy, fertile female and potential mother. Instead, as each month compounds the feeling of failure, she loses the identity of fertile woman and replaces it with that of infertile woman. Difficulty in believing in the pregnancy may be a defence mechanism against further failure. The woman may be unable to lose her infertile identity, especially as the problem that caused her to develop that identity has been bypassed rather than solved. Once the child is born, she will be infertile again, not a healthy, fertile woman who will become pregnant again normally when she chooses (Dunnington & Glazer 1991).

The midwife who is aware of these potential problems should help the woman to accept and enjoy her pregnancy. It would help if, like any other pregnant woman, she were encouraged to discuss her fears and worries about the pregnancy and her ability to cope when the baby is born. She may find reassurance in being told that most women experience fears and worries at some time during their pregnancies, regardless of the conceptional origin.

It would be helpful if, with the woman's consent, the named midwife or head professional could liaise with the counsellors at the fertility treatment centre. This would enable information about any problems identified before conception to be shared. Together, the counsellor, the woman and her partner could make suggestions to the midwife on how the woman can make the transition from seeing herself as infertile and undergoing treatment, to seeing herself as a healthy woman expecting a baby and being a partner with the named midwife in her own and her baby's care.

The woman's care should be carefully planned by the midwife using one of the theoretical models available (Crichton 1993; Bryar 1995). The spiritual, psychological, physiological and sociocultural needs of the woman and her partner will all need to be taken into account.

These measures should encourage the development of a trusting relationship between the couple and the midwife. The benefits of the therapeutic relationship include early detection of psychological or emotional problems and the opportunity for early advice or referral where necessary.

ANTENATAL SCREENING

Screening for fetal abnormality poses problems that can further affect acceptance of the pregnancy. When there has been a delay in achieving a successful conception, women are more likely to be in the at-risk age group for congenital abnormalities in the fetus. Screening will be offered, and in many cases this will include the Triple test (Decrespigny 1991), a non-invasive procedure that would give the woman a clearer knowledge of her individual risk of carrying a child with Down syndrome. However, should the projected risk of the child being affected prove to be higher than

average, the couple will have to make the difficult choice between not accepting any further screening (despite the chance of a higher than average risk of congenital abnormality) or undergoing an invasive procedure such as amniocentesis.

If the couple decline further screening, they will need much support and understanding from their carers during the subsequent months until the child is born and its state of health is known. If the couple do decide to undergo further diagnostic tests, however, it should be remembered that screening itself is based on the assumption that therapeutic termination of pregnancy is an acceptable option. Couples should not be considered for invasive screening unless they have carefully considered the implications of this. The psychological stress of considering terminating a pregnancy that has been so difficult to achieve is enormous. Those who do choose an invasive procedure must also be made aware that in doing so they are accepting a small associated risk of miscarriage in what may be their only successful conception. The couple must be given the opportunity to discuss their worries and should be given honest and up to date information, within the counselling session, on the level of risk involved and the degree of accuracy in testing.

The couple should be supported in whatever decision they make regarding screening, even if it goes against the advice given to them by the professionals. At the appropriate time, the midwife should be in a position to refer the couple to any appropriate support agencies, either to help prepare them for the birth of a handicapped child or to support them following a termination for fetal abnormality.

MULTIPLE PREGNANCY

The incidence of multiple birth is considerably higher after most forms of assisted conception than it is after spontaneous conception. In 1990, there were 20 per cent more twin pregnancies and 4 per cent more triplet pregnancies among couples achieving pregnancy after assisted conception than in the population at large (Kon 1993). This brings with it its own problems (Denton 1996). Parents expecting more than one baby should be given as much information, advice and support as possible (Davies 1995).

In certain circumstances, selective reduction (selective feticide) may be offered to maintain the woman's health and to optimise the chances of the remaining gestation sacs maturing to term (Howie 1990). This procedure should be unnecessary for pregnancies created nowadays as a result of IVF or GIFT (gamete intra-fallopian transfer), as there is now a limit of three or even two eggs or embryos being replaced in any one treatment cycle (Price 1990). However, it may still be a necessary option when the pregnancy is multiple as a result of super-ovulation therapy and may also be considered when one fetus in a multiple pregnancy has a congenital abnormality.

The couple in such a situation will have to make the difficult decision of whether to sacrifice one or more potential children to enhance the chances of survival for the remaining fetus(es). They have to make this choice knowing that the procedure may result in total pregnancy loss. Many individuals suffer long-term depression following selective reduction and will need the non-judgemental support of family, friends and carers at this difficult time to help them cope (Howie 1990).

Provision of fertility treatment on the NHS is not available throughout the UK. Many parents may therefore have already spent large sums of money achieving the longed-for pregnancy. Some may even have sold their house or amassed debts. The realisation that they are not expecting one baby, but two or even three, may therefore increase financial stress at a time when this can be ill afforded. The extra financial burden of a multiple pregnancy may put great strain upon a relationship. Practical help, such as organising a home help when the babies are born, may be necessary. If income support or other benefits are applicable, they should be claimed, and the services of a social worker should be offered where appropriate. The midwife should also refer the couple to the local support agencies (such as the Twins and Multiple Births Association) early in the pregnancy, which can help them to prepare themselves realistically for a multiple birth and offer assistance with the acquisition of baby equipment in cases of need.

The extra medical intervention associated with multiple births is well documented (Ghazi *et al.* 1991; Rufat *et al.* 1994), as is the increased (if sometimes unnecessary) intervention rate with the more mature primagravida (Silverton 1993). Many women pregnant following assisted conception will fall into one if not both of these categories and find themselves exposed to this heightened medical attention. MacFarlane *et al.* (1990) report that the higher obstetric intervention rate can be attributed to the parents' excessive anxieties and the obstetrician's concern with the 'precious pregnancy'. The effects of this on the development of parent–child relationships are also well documented (Bryan 1989; Golombok *et al.* 1995).

NURTURING SELF-CONFIDENCE

Because women often have increased anxiety levels during pregnancy, they may in fact welcome extra attention from the medical team, However, instead of being reassuring, it could have the opposite effect and make the woman worry more. The midwife should recognise this as a potential problem and help the woman to maintain her optimum health during pregnancy by offering advice on diet, exercise and lifestyle. This will increase the woman's sense of wellbeing and thus increase her self-confidence, enabling her to accept her body's ability to nurture the pregnancy and thereby decrease the risk of unnecessary medical intervention.

The midwife must work in close liaison with the obstetrician responsible for the woman's care. Together they should try to achieve a happy medium: a level of intervention to ensure that the mother and fetus receive optimum care, but one which does not provoke unnecessary anxiety. The midwife should also ensure that the woman and her partner are involved in all decision making concerning her care and that they are kept fully informed throughout the pregnancy, labour and puerperium.

When caring for such couples, the midwife should be aware that they may be experiencing conflict with long-held spiritual beliefs, especially if they have decided on treatment against the teaching of their Church (Boyd *et al.* 1986). She must also be aware that some sectors of society and also some members of the nursing and midwifery professions disapprove of the practice and ethics of reproductive technology. The couple may find themselves subjected to this disapproval from family, friends, colleagues and, indirectly, even complete strangers. This disapproval can often be accompanied by painful and personal comment. The midwife caring for couples after assisted conception should consider her own feelings with care and be honest about any prejudices she herself might have. If she is the named midwife caring for a particular woman, her duty is to support the couple concerned with compassion and empathy through what could potentially be a very difficult time for them. If, for whatever reason, she feels unable to this, she should discuss her worries with her supervisor of midwives.

ACHIEVING BALANCED PARENTHOOD

After the birth of a first child, a couple become a family. Raphael-Leff (1991) suggests that couples who wish to make an integrated transition to parenthood need to renegotiate their relationship with each other first. They need to home in on their own nurturing abilities and prepare for child-rearing by analysing their own experience of being parented and resolving any conflicts from the past. This preparation could be difficult for any couple to achieve, but for the couple who have lived through the pyschological trauma of subfertility and its treatment, it may take longer, and they may need more assistance to make the smooth transition to parenthood.

Most of these couples, having reached the point of having a child, report their relationship as being strengthened by the experience, so this should enable them to support each other through the first few difficult months of adapting their lifestyles to care for a new baby.

As discussed earlier, following assisted conception many couples use denial of the pregnancy as an emotional protection against potential failure. If this is not resolved during the pregnancy, the midwife may find herself in the position of having to help them to adapt quickly to the role of parents when the child is eventually born, as it is often only when they

take the baby home that many of these couples can accept the reality of their success – that they have a child of their own at last.

LIFE WITH A NEW BABY

Couples who have had difficulty in conceiving a longed-for baby may have particularly high expectations of themselves as parents. Consequently, some may have difficulty in coping with a real child who may not live up to their idealised dream of a perfect baby (Kitzinger 1978). Parenthood may not be as glamorous as expected, and they may be disappointed by their inability to cope with the early parenting experience in general (Raphael-Leff 1991). The midwife must assure them that this is often the case with new parents, and that their confidence and ability to cope will increase each day as the family get used to each other.

Dunnington and Glazer (1991) have shown that previously infertile women expressed a lack of self-confidence in mothering the child, especially with breastfeeding, when compared with never-infertile women. This study also reported role conflict, with previously infertile women experiencing a loss of career identity during the transition to motherhood. These negative feelings could contribute to the higher levels of postnatal depression experienced by women who have had infertility problems (Kumar 1982). However, Bernstein *et al.* (1988) stated that although previously infertile women do have raised levels of depression, hostility and interpersonal sensitivity, indicating mild distress, these do not indicate serious dysfunction. However, they found that men demonstrated lower levels of hostility, possibly reflecting the healing effect of the social recognition of manhood that fatherhood conveys.

During the antenatal period, the midwife will have had the opportunity to help couples prepare realistically for life with a newborn baby. After what may have been years of avoiding being with parents of young children because of the pain it caused them, previously infertile couples will have been encouraged to mix with such people, to experience what they are really like. They should have been encouraged to join antenatal preparation groups, such as those run by the National Childbirth Trust, aquanatal classes, and local parentcraft and relaxation classes. The purpose behind joining these groups is twofold. First, the education and health benefits derived from belonging to such groups are found by many women to be valuable. Second, the groups provide an opportunity to mix with other pregnant women. Friendships often form within these groups, which can provide a valuable support network after the babies are born.

Attendance at postnatal support groups should be encouraged to continue to develop circles of friends and peers started during the antenatal period. Such groups are often initiated by the midwife and continued by the health visitor.

If the woman's career has played an important part in her life prior to giving birth, and she plans to return to work, the midwife and health visitor should give the help and information she needs, including details of local childcare facilities. If she expresses feelings of guilt at leaving her much-loved and wanted baby at home, she should be reminded that most women in the same situation will have the same feelings and that this is an entirely normal reaction. However, she may need support as she comes to terms with these feelings.

ATTITUDES TO DONOR GAMETES

Problems with the transition to parenthood have been identified in couples where donor gametes have been used, suggesting that a missing genetic link between the child and one or both parents may subsequently affect interfamily relationships (Golombok 1992). Provision is made within the Human Fertilisation and Embryology Act 1990 13(6) for the couple who receive treatment services that involve the use of donated eggs, sperm or embryos to be given a suitable opportunity to receive counselling that will be directed towards the implications of taking this proposed step (Morgan & Lee 1991). This should address the couple's ability to accept the child as 'theirs' rather than 'his', when donor eggs are used, and 'theirs' rather than 'hers', when donor sperm is used. Goode and Hahn (1993) feel that the mother's biological attachment through pregnancy offsets her lack of genetic attachment should donor eggs be used. The child in these cases will usually be considered 'theirs'.

Where donor sperm is used, the father's involvement should be encouraged throughout all stages of the pregnancy and childrearing process. This will help him to accept the child as his despite the lack of a genetic link. Section 28-2 of the Human Fertilisation and Embryology Act 1990 gives legal recognition to the child and states that the woman's husband who consents to her treatment with donor sperm will be legally recognised as the father.

Along with having to resolve their own feelings of accepting treatment using donor gametes, the couple will have to decide whether to tell family, friends, and ultimately the child of its conceptional origins. Some couples cannot accept the stigma of people knowing that the child has been born as a result of reproductive technology, and it can be even more difficult for those who have been treated using donor gametes or embryos (O'Donovan 1990). This is especially relevant when the parents feel that such knowledge may affect the child's acceptance into the wider family circle by grandparents, aunts, uncles, etc.

TO TELL OR NOT TO TELL?

Popular opinion seems to support the argument that everyone should have the right to be able to establish details of their identity as an individual human being (Morgan & Lee 1991). The advice given by social workers to parents of children conceived using AID is to share details (O'Donovan 1990). Those children in the future who are told of their conceptional origins will be able to apply to the Human Fertilisation and Embryology Authority for limited, non-identifying information about the gamete donor. This information may include such details as physical characteristics, education, occupation and general family health. The Authority will also disclose whether the child could be genetically related to a prospective partner.

Despite conventional wisdom supporting the right of the child to know its conceptional origins, it is still a very difficult decision for the parents to make. There is very little published research on the effect of conceptional origins on the psychological development of the child(ren) concerned. One can only study the experience of adopted children and those born following AID to help the parents to decide what to tell their children. If they do decide to maintain confidentiality, it may be very difficult to explain the pregnancy to family and friends who knew of the fertility problem, especially if the woman is known to be menopausal or the man to be infertile.

This may be a very stressful time for the new parents. The midwife must work within the UKCC Code of Practice and maintain confidentiality as demanded by the UKCC Code of Professional Conduct, but she could also direct the parents to counselling services, where available, to help them to see the wider aspects of their decision and help them prepare for any possible consequences of that decision. If they decide not to tell the child, they may always worry that he or she may find out accidentally. The consequences of this occurring for children born as a result of egg donation or IVF are largely unknown. This is an area in need of further research (Ethics Committee of the American Fertility Society 1990; Golombok 1992).

POTENTIAL DEVELOPMENT OF THE CHILD

Little is known on whether the intense media attention that surrounds such children or the conceptional origin in itself has any effect upon their physical and psychological development. It is known, however, that children born as a result of reproductive technology may be treated differently by their peers from those conceived normally. Friends may tease them because they 'came out of a test-tube' (Lasker & Borg 1989). Their parents have waited a long time for their 'miracle baby' and invested much of their

time, finances and lives into the child's creation. Parental expectations of the child have been shown to be very high; they are often overprotective, worrying excessively about the child's health and development, treating the child as extra special and finding it hard to let go and allow the child to develop a sense of independence (Lasker & Borg 1989; Jones 1991). The associated media hype that still surrounds these births does little to protect the family's right to privacy and may prompt the parents to continue treating the child in this way.

The children may find themselves unable to live up to their parents' high expectations and may display emotional and behavioural problems. Golombok *et al.* (1995) say that it may be that when children conceived by the new reproductive technologies develop psychological problems. the parents may attribute these problems to the conceptional origins. They then treat the child differently from parents who conceived their child naturally, who are able to look at the problem from a wider angle rather than concentrating on the one thing that makes their child different from the rest.

It is not only the parents who will be watching these children very carefully. The researchers in the field of reproductive medicine will also be studying this small select sample of children, as it is not known whether the procedures involved in this new field have a direct effect on the child's development (Medical Research Council 1990; Golombok *et al.* 1995). The small studies published to date, which include those by Mushin *et al.* (1986), Yovich *et al.* (1986) and Golombok *et al.* (1995), show that the children are intellectually developing well. However, they demonstrated a higher rate of emotional and behavioural problems among these children when compared with their peers in a nursery class. The levels of behavioural problems found were similar to those found in social services day nurseries and were more common among boys.

The midwife's role

The midwife can help to make the parents aware of the fact that these children are developing normally. If they maintain the friendships they made during pregnancy, they will be able to see other children of the same age, which will help them to accept that all children develop at their own pace but that milestones will eventually be reached. They will also be able to discuss any problems concerning the child's development and behaviour with other mothers who will probably have conceived naturally, and who are likely to be experiencing the same problems. This helps the couple realise that their child is not really any different from the rest, and they can then be more relaxed in their approach to childrearing, thus reducing the higher levels of emotional and behavioural problems identified by Golombok *et al.* (1995).

The role of other health professionals is crucial, too , as the family move from the care of the midwife into that of the health visitor. The health visitor is likely to be the main port of call for advice about any aspects of the child's development and behaviour that may give the parents cause for concern.

FUTURE DEVELOPMENTS IN THE FIELD

Pressure is increasing, internationally, to remove the secrecy from gametic donation. There is pressure in the USA and elsewhere for more information to be released, and in Sweden this has led to legislation (O'Donovan 1990). If the parents are given more information about the donor, it may help them to accept their child's behaviour and development as normal for that individual child, rather than trying to attribute any inconsistencies to genetic origins.

The number of centres offering treatment for subfertility problems is increasing, and appeals are being made by support groups such as ISSUE and CHILD (see address list below) to increase provision within the NHS (Kon 1993).

As the number of people receiving treatment increases, so also will the number of children being born as a result. All midwives will be expected to care for these women and should be able to base that care on current research findings (Bryan & Higgins 1995).

There does appear to be a consensus of opinion among the experts that the subject of parenting after infertility is in need of further research. Woollett (1989) suggests a need for more information on the transition to parenthood in terms of counselling needs. Dunnington and Glazer (1991) suggest the need for further research to fully understand the impact of infertility on early mothering behaviour.

Midwives should rise to the challenge and use their developing experience gained while caring for these women to pursue topics in this field of science, in research projects of their own. It is only by asking the relevant questions, and doing longitudinal studies with families already created by the new reproductive technologies, that we will be able to reduce the anxieties of the families currently involved and improve the experience for the families of the future.

SUMMARY

The number of pregnancies now resulting from assisted conception techniques is increasing all the time. However, most couples who have achieved a pregnancy by such a method then become consumers of the NHS maternity services like any other prospective parents. They may choose not to identify themselves as previously infertile couples, or they may not be given the opportunity to do so.

The midwife has a key role to play in supporting, advising and preparing the woman and her partner throughout the pregnancy, delivery and early postnatal period. The named midwife is the woman's key link professional and as such should be prepared to act as guide, friend and advocate at a crucial time in the woman's life.

The midwife needs to understand that the couple may have difficulty coming to terms with the reality of the pregnancy and is uniquely placed to help them to redefine their self-concept from that of 'infertile couple' to 'prospective parents'. The midwife should give the woman and her partner space to express their anxieties about the pregnancy itself, and about how they will manage as parents after the baby's birth. This may be particularly necessary if more than one baby is expected.

The parents-to-be will need to be informed about the various organisations that can offer them support, be it practical, educational, social or financial. The midwife should ensure that she has the relevant up to date information available.

Should the parents be in one of the 'target groups' for invasive procedures, such as diagnostic techniques or selective reduction, the midwife will need to be particularly supportive and empathic as she gives the couple the information and the time necessary to make the decision that is best for them.

Once the baby has been born, the mother may be at risk of postnatal depression or she may have difficulty bonding with the real child. The midwife should be alert to the woman's state of mind and emotions and, as the key link professional, may be the first person to notice whether specialist referral is indicated.

The challenge to today's midwife is to allow the woman to be a full partner in her own care. In a situation such as pregnancy following assisted conception, months, perhaps years, of feeling passive and disempowered, of having things 'done to her', might have been experienced before the achievement of a pregnancy. In such situations, the midwife's role in undoing some of these negative experiences and restoring the woman's sense of dignity and 'normality' is crucial.

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USEFUL ADDRESSES

British Infertility Counselling Association
69 Bibision Street
Sheffield S1 4GE

CHILD
Charter House
43 St Leonards Road
Bexhill-on-Sea
East Sussex TN40 1JA Tel: 01424 732361

Provides information, counselling and support to infertile couples.

Human Fertilisation and Embryology Authority
Paxton House
30 Artillery Lane
London E1 7LS Tel: 0171-377 5077
Fax: 0171-377 1871

ISSUE (The National Fertility Association)
509 Aldridge Road
Great Barr
Birmingham B44 8NA Tel: 0121-344 4414
Fax: 0121-344 4336

Provides continuing help for people experiencing difficulty in conception.

TAMBA (The Twins and Multiple Births Association)
59 Sunnyside
Worksop
Notts. S81 7LN Tel: (01909) 479250

Supports families with twins, triplets or more through a network of over 200 Twins Clubs throughout the UK. Promotes understanding among the public and medical and education professions of the needs of such families. Specialist support groups for parents of 'supertwins' (three or more) with special needs. The Health and Education Group provides a parents–professional partnership. Students' packs and speakers are available.

CHAPTER TEN

Drug misuse and pregnancy

Catherine Siney

Pregnant women with a history of drug misuse present midwives with a particular set of challenges. This chapter explores these and suggests some strategies for responding to them.

Most of us indulge in some degree of drug use – the comforting cup of coffee, the sociable alcoholic drink, the welcome cigarette – so it is important to define exactly what is meant by the terms 'drug misuse', 'drug dependence' and 'problem drug taker'.

The Department of Health (1991) defines 'drug misuse' as:

> 'drug taking which is hazardous or harmful and unsanctioned by professional or cultural standards. It is broadly equivalent to terms such as 'drug abuse' and 'problem drug taking'.

The Department of Health (1991) definition of 'drug dependence' is:

> the altered physical and psychological state which results in disturbed physical and mental functioning when the drug is abruptly discontinued. It is broadly equivalent to 'addiction'. Not all drug misusers are drug dependent.

The United Kingdom Advisory Council on the Misuse of Drugs (1982) definition of the problem drug taker is:

> any person who experiences social, psychological, physical or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her own use of drugs or chemical substances.

Pregnancy in female drug misusers has been a recognised phenomenon since the mid 1980s. However, there has been little change in the midwifery/obstetric management of these women in the UK (Fraser 1983; Kroll 1986; Gerada *et al.* 1990; Siney 1995). This is probably due to the lack of large-scale, up to date research in the care of pregnant drug users, which is in turn due to the failure of maternity services to identify the women concerned (Gerada *et al.* 1990). While pregnant drug users are

regarded as a 'high-risk' obstetric group (Siney 1995), responding to their needs in the context of hospital antenatal care, or indeed any antenatal care, has proved a particular challenge.

HIV and AIDS in relation to drug misuse is not discussed in this chapter, being too large a subject to address only in part. It is to be hoped, however, that all clinical midwifery practice is based on an awareness of the high-risk potential of all body fluids from all women.

A WOMAN-CENTRED SERVICE

Following work undertaken in Liverpool (an area nationally acknowledged to have a large number of drug misusers, particularly opiate users), a midwife-led system of care was designed in an attempt to make both maternity and gynaecology in general, and antenatal services in particular, more 'woman-centred' and therefore 'user friendly'.

The system was audited after the first year and a case–control study completed in 1993 (Siney *et al.* 1995). The care provided now enables women to look forward to their baby's birth with a level of optimism comparable to that enjoyed by non-drug-using women. Countrywide, however, there are different approaches to the care of pregnant women who use illegal drugs. It would appear that some women fear that they might encounter punitive or judgemental behaviour from midwifery and obstetric staff.

While it is accepted that any regular drug use (whether illicit or prescribed) during pregnancy will place a woman in a 'high-risk' category, a system of care that allows a woman to receive antenatal care in a relaxed way, allowing her to be open about her drug use, will enable health care providers to give her appropriate advice and build up a basis of knowledge about this largely hidden problem.

Identifying the client group

Doctors are obliged by law to notify the Addicts Index at the Home Office of contact with anyone they consider to be, or have reasonable grounds to suspect of being, addicted to controlled drugs. They should also report details of these patients to the appropriate Regional Drug Misuse Database. Compulsory admission to hospital under the Mental Health Act may be justified for a drug misuser who is also suffering from mental disorder, but drug misuse alone is not sufficient grounds for this.

An accurate estimate of the number of women of childbearing age in the UK is difficult to gauge. Drug misuse affects males and females equally, but patterns of drug use differ between the sexes. The availability of treatment programmes varies throughout the UK but, where programmes are available, they generally give pregnant women priority of access.

Because most drug services are geared to opiate users, there is a problem in identifying users of other drugs, such as cocaine. Cocaine is becoming an increasing problem in the UK, but the challenge it presents to the midwifery and obstetric services has much in common with that posed by other drugs. The best way to encourage both registered and non-registered drug users to identify themselves and attend for antenatal care is to develop an attractive woman-centred and non-judgemental service that guarantees confidentiality.

In some areas, midwifery and obstetric services have no information about known or registered drug misusers. A survey of obstetric units in England and Wales that asked for the actual or estimated number of babies born to drug-dependent women in the previous year, and compared that number with the number of drug-using women identified to regional databases, indicated that there were probably a large number of women not being identified (Morrison & Siney 1995). There are, of course, some areas where this is not the case.

A persuasive reason for midwives to identify which of the women in their caseload use drugs is to avoid them becoming even more marginalised by turning up 'unbooked' at delivery time. Early identification may also make paediatric problems in the postnatal period easier to deal with. Moreover, it is part of the midwifery challenge to ensure that women who might be considered to be 'high risk', and who might not be comfortable attending hospital or GP antenatal clinics, should have some antenatal care in a setting in which they feel at ease.

Another important clinical reason for identifying drug misusers who are pregnant is to ensure that they are aware of the risks of sudden opiate withdrawal. Cocaine and other stimulants can be stopped immediately without ill effects. If a pregnant woman uses opiates, however, her baby can suffer acute withdrawal symptoms, which may cause distress, may precipitate labour and may even be fatal. If an opiate-dependent woman wishes either to reduce or to stop using drugs, this should be done in a controlled manner. This can be achieved on either an inpatient or an outpatient basis.

There are many reasons why women do not identify themselves as drug misusers, the main one being that the attitudes of many people, particularly those involved in child care, towards drug misusers can be perceived to be judgemental. Consequently, women may fear that the professionals will assume that they will make bad mothers. According to the Department of Health (1991), being a drug user does not preclude the presence of parenting skills and is not necessarily a reason to separate mother and child. Any changes in attitude, however, are not universal.

Another reason why women do not identify themselves as drug users may be that they fear they will be treated differently from other pregnant or newly delivered women while in hospital. Such differences in treatment

will probably be on the grounds that they will automatically be considered to be at higher risk from bloodborne infections (particularly HIV and hepatitis B and C) than the general public who do not admit to drug misuse or high-risk sexual behaviour.

Apart from the women's confidentiality and dignity, the risks to staff of being selective about the way they apply stringent principles of infection control cannot be overemphasised. All body fluids from all women should be considered to be risky to staff, and therefore clinical practices should be of the highest standard in every case and not just where a woman is known to be HIV positive or an intravenous drug user.

Trust is essential

It is important to build up trust, not only between women and those who work in the maternity services, but also between all professionals who work with drug-misusing women. This is equally true in areas where there are no statutory drug services. It is important that the women know that they will be cared for as other women are, and that they will not encounter adverse discrimination. Pregnant women who are comfortable about discussing their drug use with midwives enable the development of a real partnership in care. Always providing that confidentiality is not infringed, the expertise gained by the midwife and the outcomes of the pregnancies can then be shared with all agencies, both statutory and non-statutory. The more such sharing and interaction is possible, the more accurate information about the effects of drugs on pregnancy and the neonate will become available and can be given to drug users before they become pregnant.

THE LIVERPOOL EXPERIENCE

Attitudes can be positive or negative. Starting with the hypothesis that a supportive staff attitude would be most helpful to the client group, some drug awareness study days were set up in Liverpool as an initial step. Managerial, medical, nursing and social work staff from the local statutory drug service were invited to talk to the hospital and community staff. Information was given about drugs and treatment programmes, prescription of an opiate substitute (methadone) both in pregnancy and in general, and about drug misuse/dependency and childcare issues. The study days were popular and well attended. Following on from them, regular updating lectures are held during each year, and all grades of staff (both professional and ancillary) are welcome.

There was initially some resistance to the outreach work following in the wake of the study days, but this was overcome by the fact that although more drug misusers were identified as a result of it, the majority

in reality caused no extra work or problems for the staff. There is now a simple management guideline in place.

A specialist midwife liaises with all services who work with drug misusers, be they statutory or non-statutory. Information that helps the drug-using woman to go through the maternity services is exchanged, with her knowledge. Any woman who admits drug misuse at any time is referred to the specialist midwife.

It is important for women to feel that they can talk truthfully at antenatal interviews. The word 'use' instead of 'take' in relation to drugs is recognised by a drug user but will probably mean nothing to a non-drug user. By the language they speak, staff can indicate a non-judgemental attitude. This in turn enables the women to ask questions about the effects of drug use on their fetus and allows staff to explain the principles that will be followed in the planning of maternity care and the care of the newborn child.

A woman who is on a controlled programme of opiate withdrawal and receiving a regular methadone (opiate substitute) prescription is likely to see herself no longer as an addict. People in this situation may refer to the methadone as 'medicine' and can easily be offended if this is forgotten.

Access to systems of care

In Liverpool, referrals are made to the specialist midwife from drug services and GPs who prescribe methadone to their patients, and the probation service and social services; women also self-refer. Antenatal care and advice is offered freely to women whether or not they are registered for treatment, and whether or not they are booked into a hospital for the birth. If the women want to deliver their babies at the Liverpool Women's Hospital, they can be booked by the specialist midwife wherever she sees them. Antenatal visits should be arranged at least monthly at any site, including drug clinics, GP surgeries and the hospital. No extra visits to hospital are required purely because of drug addiction. When attending hospital, the women are seen wherever possible by the same senior doctor (either consultant or senior registrar), thus giving some continuity of obstetric care.

The hospital pharmacy is kept up to date with accurate information about the amount of methadone prescribed and its approximate equivalent in 'street opiates' for women who are not 'notified' drug users. This should enable a guaranteed supply of methadone for all women who are admitted to hospital.

In Liverpool, a guideline for the treatment and care of infants of drug misusers has been designed, together with a non-subjective neonatal opiate withdrawal chart (Figure 10.1).

Figure 10.1 *Neonatal drug withdrawal chart*

Name: ____________ **Casenote No:** ________ **D.O.B.:** ________ **Gestation:** _____

All infants of drug misusers must have observations started from birth.
Observations made post-feed.
Severe symptoms – please tick (✓) if present.

Date:								
Time:								
1. Convulsions								
2. Tremors when undisturbed. Non-stop high pitched cry. Sleeps < 1 h after good feed. (All must be present to score)								
3. Watery stools or projectile vomiting or requirement of tube feeds.								
Signature:								

Date:								
Time:								
1. Convulsions								
2. Tremors when undisturbed. Non-stop high pitched cry. Sleeps < 1 h after good feed. (All must be present to score)								
3. Watery stools or projectile vomiting or requirement of tube feeds.								
Signature:								

Date:								
Time:								
1. Convulsions								
2. Tremors when undisturbed. Non-stop high pitched cry. Sleeps < 1 h after good feed. (All must be present to score)								
3. Watery stools or projectile vomiting or requirement of tube feeds.								
Signature:								

Instructions for Treatment

Minor symptoms **need not** be recorded. These may include:

*Tremors when disturbed
*Pyrexia of unknown origin,
*Frequent yawning
*Poor feeding/regurgitation
*Respiration > 60 per minute,
*Sweating,
*Sneezing/nasal stuffiness,
*Loose stools.

If treatment of any of the 3 **severe** symptoms is not judged clinically necessary, then reasons must be recorded in casenotes.

Treatment:

Dose:

0.04 mg/kg morphine sulphate orally, every 4 hours.

Commence treatment 4 hourly ('treatment level5'). Then reduce the level of treatment every 24 hours as follows if severe symptoms are not present:

0.04mg/kg morphine sulphate 6 hourly ('treatment level 4')
0.04mg/kg morphine sulphate 8 hourly ('treatment level 3')
0.04mg/kg morphine sulphate 12 hourly ('treatment level 2')
0.04mg/kg morphine sulphate daily ('treatment level 1')

If severe symptoms persist, do not reduce the level of treatment

If severe symptoms persist on 4 hourly morphine ('treatment level 5') discuss, with a senior paediatrician, the possibility of increasing the dose of morphine or adding other medication.

The intention of these is to make it easy for the midwife to monitor the baby whatever her experience of drug misuse. This enables the mother to see that there can be no bias in monitoring and also ensures that babies who require treatment are treated both when necessary and appropriately. There is no difference in the quality of care received by drug-using (compared with non-drug-using) mothers, either during labour or in the postnatal period. Nor are the drug-using mothers and their babies cared for separately from either each other or others. This egalitarian approach maximises the likelihood of the woman's privacy, dignity and confidentiality being maintained while she is in hospital.

Regular, informal antenatal meetings are held with the senior hospital social worker, the liaison health visitor and the specialist liaison midwife, which include input from any key workers. This has made it possible to develop a discharge policy that can be discussed with the women during the course of the pregnancy. If there are no statutory reasons for a child protection conference, and mother and baby are both medically fit, they are transferred to community midwifery care following paediatric review 72 to 96 hours after delivery. If required, statutory child protection conferences are arranged before delivery so that the women's admission to, and transfer from, hospital can be as well organised as possible.

The maternity service for drug users would not be possible without the support of all agencies involved in the care of female drug misusers. Although the specialist drug liaison midwife is funded from obstetric resources, the support and information provision from other services is essential to the provision of optimum antenatal care.

Audit

It became obvious by the uptake that the service provided in Liverpool was popular with drug misusers. However, some form of audit was needed to measure the system of care that had evolved and its outcome for the women involved.

The resultant case–control study considered the care and progress of over 100 women. All of these were on a methadone programme with or without other drugs, all had received regular antenatal care and all had delivered in the unit during a 2-year period. The study, which is described in more detail elsewhere (Siney *et al.* 1995), aimed to test the hypothesis that regular antenatal care and a controlled methadone prescription minimised the risks incurred by opiate-dependent women and their babies, in comparison with their non-drug-using counterparts.

The results of the study confirmed the hypothesis. There was no infant or maternal mortality and no infant morbidity attributable to drug misuse. However, two babies born to drug-using mothers had congenital malformations – one a cleft lip and palate, and one severe hydrocephalus that had