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Midwifery care for travellers

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In recent years, sensational reporting by the media and the government response to travellers have raised the profile of this heterogeneous group of people. The aims of this chapter are, first, to consider travelling women within their social context and, second, to explore how midwives might offer appropriate care as indicated by an examination of health care issues and research evidence.

During the antenatal, intrapartum and postnatal periods, a travelling woman has the same needs as any other woman. It is anticipated that an understanding of the particular context of the travellers' culture and lifestyle will help the midwife to offer appropriate care.

For the purposes of this chapter, the term 'travellers' will include all travelling people, gypsies and tinkers, and, generally, a distinction between 'new' travellers and other travellers will not be drawn. A definition by Hussey (1990) enables one development of a broader perspective: 'people who may or may not share a language... but who do have a commitment to a life that is similar'.

There are a number of projects across the country seeking to meet the challenges of providing health care to travellers (Eckford 1990; Rose 1993; Tyler 1993; J. Wilkins, personal communication, 1993). However, although there is a growing body of literature by health care professionals, there is a dearth of midwifery-specific sources. Yet the midwife, too, is part of the multidisciplinary team who will be involved in offering care to women and their families.

TRAVELLERS WITHIN THEIR SOCIAL CONTEXT

Effective discussion of midwifery care provision for travellers is impossible without first exploring the context of care.

A problem of definition

Liegeois (1987) suggests the framework of four distinct traveller groups in the UK:

- North Welsh Kale
- South Western and English Romanichals
- Irish Pares and Minciers
- Scottish travellers.

The 1968 Caravan Sites Act includes 'Persons of nomadic habit of life whatever their face or origin' but it does not include 'members of an organised group of travelling showmen, or persons engaged in travelling together as such'. This definition is restated in the Criminal Justice and Public Order Act (1994) and obviously excludes certain people who would identify themselves as 'travellers'.

There is a notion that somehow there is a true-blooded gypsy and that others have merely appropriated the term. The romantic image applied to the Romanies may result in a stereotype that dehumanises them and labels them as exotic. This may cause them to be viewed as separate and alien from the wider population but also lends strength to the concept of the true and traditional traveller – in contrast to others who 'sponge' and 'scrounge' off society (Bates 1989). This has been highlighted particularly by the 'new' travellers who are not seen as 'real' or genuine travellers. Hawes and Perez (1995, p 8) suggest that it is not possible to 'discuss Gypsy issues without acknowledging that large numbers of people who live in caravans do not conform to the generally accepted notions of what is meant by that term'.

Although it is true that there are some culturally specific areas for some groups, many of the issues that face any traveller are similar. More than a third of local authorities would evict a newly delivered woman from an unauthorised site (Fletcher 1993), and in some areas women are not immune from harassment even when they are in labour (Sadler 1993).

In response to findings from the Maternity Alliance concerning the health of travelling women, a group of individuals from Save the Children Fund and other interested parties set up the 'Safe Childbirth for Travellers' campaign in 1990. The primary focus was to stop the eviction of pregnant and newly delivered women from sites and to ensure that local authorities were aware of the health circumstances of travelling families and took the needs of pregnant women, mothers and babies into account before considering eviction. This forward-thinking campaign anticipated the Criminal Justice and Public Order Act, which received Royal Assent on 3 November 1994. The 1968 Caravan Sites Act, whereby local authorities had a duty to provide sites for travellers, was repealed.

Local authorities may now use their discretion with regard to site provision and maintenance. Central government funding for site provision and maintenance is no longer available, and local authority and police powers to stop unauthorised camping as well as the number of eviction orders, without recourse to the court, have increased (Lloyd 1994; Maternity

Action 1995; MIDIRS 1995). With a reduction in site provision, it is felt that homelessness and imprisonment for failure to comply with eviction orders may increase (Davis *et al.* 1994). Access to health care may further be reduced and the statutory duties of the Children Act (1989) may not be fulfilled. The UN Committee on the Convention of Children's Rights in 1995 considered that the Act would have a major impact on the rights of gypsies and travellers.

However, guidelines from the Department of the Environment, entitled 'Gypsy Sites Policy and Unauthorised Camping' (DoE 1994) may be used in dealing with local authorities when travelling clients in their care are faced with possible eviction. Point 9 of these guidelines suggests that local authorities 'should use their powers in a humane and compassionate fashion'. Point 13 states, 'When deciding to proceed with an eviction, they should liaise with relevant statutory agencies, particularly where pregnant women or newly born children are involved, to ensure that those agencies are not prevented from fulfilling their obligations towards these persons'.

In September 1995, eviction procedures were challenged by a group of travellers in Lincolnshire and Sussex. Mr Justice Stalley ruled that Wealden District Council and Lincolnshire County Council were 'legally wrong in failing to take account of the human factor' (Gibb 1995). Proper enquiry into the needs of travelling people, including pregnant women, was not made before evicting them, and the eviction order was overturned in the Wealden case.

Safe Childbirth for Travellers is persistently refocusing the campaign but would wish to monitor the effects of the 1995 Act on the case of women and their children. A positive strategy is for midwives to give appropriate information to the campaign; their address can be found at the end of the chapter. They can also be contacted for help and information.

Reduced access to maternity care is not purely a geographical concept but may be due to ineffective communication. There is evidence that travellers are considered to be a deviant group and are on the receiving end of active discrimination (Kenrick & Puxon 1972; Okely 1983; Feder 1989; Durward 1990). An awareness of travelling people and their individual perspectives is vital for any midwife providing care. More information about their culture might decrease discrimination and improve the standard of health care provided (Feder 1989).

History

Okely (1983) tells us that 'The history of the Gypsies is marked by attempts to exercise, disperse, control, assimilate or destroy them'. In Europe, there was a general belief that they brought death and disease (Kenrick & Puxon 1972). Although there was a theory that they originated in Egypt, records of travellers in England have been known since the sixteenth century.

Henry VIII ordered their expulsion, and those who did not leave were judged as felons and executed.

In the Second World War, they were branded as 'antisocials' and more than 250 000 were executed by the Nazis. More recently, they have been the victims of 'ethnic cleansing' in Romania (Bridge 1993).

In England, Wales and Scotland, there are thought to be around 12 000 'caravans' or household groups, but this may be an underestimation (Fletcher 1993). The most common geographical areas of habitation are East Anglia, Kent, Wales, Scotland, London and urban areas of the Midlands.

Cultural issues

For some established travelling people, there are common factors that may affect their lifestyle, health and acceptability of health care.

Travelling people generally have a different attitude to work from that found in the wider society. Preferring to be self-employed, they see work as something to be integrated into their lifestyle – although the recession has brought constraints to their working patterns. Helping with seasonal farm work and calling on houses has been replaced by scrap metal dealing, manual work on the roads, carpet selling and even landscape gardening (Okely 1983; E. Fletcher, personal communication, 1993). However, there is an increase in the numbers of men on income support and of women being 'trailer bound'. Since travelling people live alongside, yet independently of, the wider society, this loss of their own employment has been disempowering. This has led to an increase in alcoholism, smoking and marital disharmony (Crout 1987). Investment of resources is in items that may easily be exchanged for cash (such as jewellery or cars) and definitely not in building societies or banks.

The travelling society is close knit, and strong ties are made through kinship and marriage. It is, in essence, also a patriarchal society. The outsider, called the 'giorgio', is viewed with suspicion, and it may be salutary to realise that the giorgio may be considered as dirty or polluting (Okely 1983).

It is generally expected that women will marry early and be pregnant within 18 months (Raper 1986). In the past, families were large, but this is changing. Research in Avon 1990–2 found that the main reasons for reduced family size were physical exhaustion and financial hardship (Hawes & Perez 1995).

Living conditions

The trailer is nearly always scrupulously clean, even though the quality and size will vary. Better trailers may have coal fires, while others may have poor insulation and Calor gas heating, leading to condensation. Trav-

ellers choose to live in a trailer and may have a mobile lifestyle. Taking up residence in a house is normally due to shortage of sites, rather than through choice.

Where there is a problem with sites, some travelling families may be housed in bed and breakfast hostels or other buildings. It seems that public housing options are not easily obtained (Davis *et al.* 1994). Living in a house may impose difficulties and restrictions not encountered in a caravan, and adjusting to the differences may be hard. Some travellers appear to find the space overwhelming, choosing to live in one room only. Repairs may provoke anxieties – it is not possible to take a broken window from a house to be mended as it is with a trailer window.

Hygiene rules are described by Okely (1983). These reflect the way in which travellers live and their view of the giorgio, and go some considerable way to explaining why they see house-dwellers as dirty. The outside is seen as a covering for the inside, and anything internal must be clean. This is expressed in the belief that polluting dirt may be visible yet must be separate. Therefore the site need not necessarily be tidy and clean, but the inside of the caravan must. There is a definite system for ensuring that washing of the body, clothes and cooking utensils are undertaken in separate places in the caravan, as well as in separate bowls. Kate, a travelling woman, describes the system:

We have a clean bowl to wash up in, a different bowl to wash our face in and a different bowl to wash our clothes in. Inside toilets are thought to be polluting and therefore often not used in the trailer. In the past, menstruating women and those who have given birth were also considered to be polluting.

According to Fletcher (1993), if a death occurs the trailer must be burnt and the family must move on. On a settled site, this may mean moving pitches.

Travellers and the giorgio

There is an uneasy relationship between travellers and the wider society. Hostility is frequently directed towards travellers, their presence in an area is seen to 'lower the tone' and there are many examples of open aggression towards them (Save the Children Fund 1992). Constant eviction from sites and threats and fears of abuse are not uncommon.

Given the pervasive and deeply rooted mistrust, it is hardly surprising that travellers do not readily accept outsiders and that their policy should be that 'it is safest to mistrust giorgios'. For midwifery care to succeed, there needs to be outreach on the part of the midwife, enabling a movement from distrust through knowledge to a degree of mutual under-

standing. Midwives need to begin by attempting to understand why the distrust is there in the first place.

The 1993 Midwives' Rules state that 'The continued attendance of a midwife on a mother and baby is requisite' for a minimum of 10 days and a maximum of 28. Post delivery, women must be visited on site. The challenge implicit in visiting travelling women is to optimise their care provision, and a midwife who has already built up a relationship with a woman is likely to be able to provide better care than one who has not. Although not always easy to achieve, this aim can be facilitated through continuity of care.

Site provision

Provision of sites may vary in quality and there is a shortfall. The impact of the Criminal Justice Bill has yet to be fully revealed, but site provision is a key issue for the travellers' lifestyle and health. Permanent sites, which have bathroom and washing facilities per pitch, may not be without drawbacks. Travellers who might not normally choose to live together find themselves on the same site – which may lead to tensions and difficulties. Even official sites, such as the one described below, have been shown to be inadequate in various amenities:

Regulations state that there should be only one caravan per pitch, but every pitch has two, sometimes three, caravans. There are large banks of rubble and soil dividing up the site and the caravans. Children use them as play areas while family pets and other animals use the banks as places to deposit excreta. (Batstone 1993)

HEALTH ISSUES

Many sources quote poor general health issues. Environmental aspects are detrimental to health (Riverside HA 1992). Smoking may be common (Riverside HA 1992), and alcoholism and obesity may be problematic (Crout 1987). The sites themselves may be environmentally unfriendly and less than ideal for women who have tiny babies or who are pregnant. Amenities may be limited, and the lack of basic requirements such as water or toilet facilities compound the difficulties for both the women themselves and the professionals caring for them.

The Northern Gypsy Survey (1993) interviewed 63 families and found that 45 per cent requested improved sanitation and 37 per cent felt that moving regularly affected their health care.

Lack of knowledge about general health issues and bodily awareness in women is common. Their poor understanding of their bodies may lead to

misunderstandings of health issues. However, it is generally felt that one-to-one work, through designated health workers, is gradually changing the situation.

Travellers themselves state their needs as being secure, safe sites with sanitation, water supplies and freedom from environmental problems. Health needs are secondary to these more pressing ones (Feder 1990). This raises the issue of the focus of 'health care' research, which may fail to look at the real issues and lead to victim blaming and further stereotyping.

Maternal and child health

In 1988, Pahl and Vaile published their results of interviews undertaken by health visitors in Kent on 263 mothers, all with at least one child under the age of 15 years. The women had had 814 pregnancies in all. The results demonstrated a dissatisfaction with site provision, 14 per cent having no mains water supply, 21 per cent no mains electricity and 33 per cent no toilets. Only 6 per cent of the women stated that they had not been ill in the previous 5 years. Among the sample, 55 per cent had received no antenatal care when pregnant, 97 per cent had delivered in hospital and the majority of deliveries were normal. Low birthweight occurred in 12.8 per cent of the sample. The stillbirth and neonatal death rates (per 1000 total births) were 12.0 and 16.0 respectively. These figures are above the national average, but the study has been criticised since there was no way to verify the self-reporting (Feder 1989). Furthermore, health visitors working with travellers report no unusual incidence of low birthweight or raised complications in childhood (L. Dodge, personal communication, 1993; E. Fletcher, personal communication, 1993).

The Association of Metropolitan Authorities (AMA) surveyed its 67 member authorities on their policy towards the eviction of pregnant women in July–October 1988. Of 43 respondents, 16 said they would evict pregnant women, 13 would evict women close to birth, and 15 would evict mothers with a newborn baby (Durward 1990).

Among the cases collected by Save the Children Fund is that of Mary, 19 years old, 7¹/₂ months pregnant and living on an unauthorised site. The local council decided to evict the travellers, although the land was derelict. The travellers decided to move on before being evicted, and eventually Mary moved up north to be near friends. For the last part of her journey, she was in labour and, for the delivery, had to go to an unfamiliar hospital (Morton 1992). Another case from the same collection is that of a young woman in late pregnancy and unwell, waiting for an ambulance to take her to hospital, who was meanwhile barricaded in by the local council with earth mounds that caused severe problems with access (Morton 1992).

Moving on in pregnancy is not only stressful but also means that the woman may not be able to visit the hospital where she has been booked or

achieve any form of continuity of care (Sadler 1993). This may reinforce the commonly held view of travellers as being deviant, non-compliant and uncaring about their unborn child. They are seen either as 'late bookers' or as poor attenders, 'defaulters'. Compounding this situation is the difficulty of not having a postal address at which they might be contacted. Furthermore, it should not be assumed that all travelling women can necessarily read.

The midwife should know what action she can take as the woman's advocate to prevent eviction or to ensure that services are provided. She can contact the local authority and ask for a pregnant or recently delivered woman not to be evicted or moved on, by using the Department of Environment guidelines (DoE 1994) (Fletcher 1993). She can also contact the environmental health officer to ensure that services will be provided as legally required (MIDIRS 1995). An example of a midwife acting on her client's behalf is given by Harold (1993). The client was on Forestry Commission land and wished to have a home delivery. The Forestry Commission wished to evict the woman, but the midwife acted as her advocate and negotiated with the Commission's personnel, thereby forestalling the eviction until after the woman had delivered.

Access to care has been highlighted as problematic for many women (Department of Health 1993). Furthermore, the Chief Medical Officer has stated that the NHS must take positive steps to eliminate discrimination (Calman 1992). Some positive steps to address this challenge might include:

- redirection of resources from high-tech hospitals to community care – more midwives who are able to provide care in the community and facilitate travelling women to use existing services;
- legislation to protect pregnant women and newly delivered mothers from eviction;
- a friendly reception in hospital and clinics and a real attempt 'to understand and not to try and change their ways' (S. Salter, personal communication, 1993)
- provision of health promotion information in an acceptable format.

Access includes not only knowing where to go and being physically present but also involves the interaction that takes place between the care-giver and the client. It is all too possible for a spiral of poor communication to occur. Take, for example, the woman who, despite having been born in England, had a strong Southern Irish accent. She had previously delivered a baby at the hospital where she was booking for the second time. The receptionist at the antenatal clinic told that woman that she would not be entitled to NHS treatment. Despite her protests about having been born in England, she was sent a bill for £1895 following the birth of the baby. Her communication skills had been insufficient to argue her case and the recep-

tionist had acted in a judgemental way. One of the challenges facing midwives is that of establishing how such situations can be prevented.

MIDWIFERY ISSUES

The woman's position is clearly defined by many travellers, and there are certain issues which are a woman's domain. If a midwife seeks to discuss 'taboo' issues with the men, she should expect to encounter hostility and possibly rejection. It is quite normal for the men to disappear from the caravan when the midwife comes to visit – this should not be taken as a sign of unfriendliness. Many travelling women view pregnancy as their private business, not to be discussed by other members of the community (L. Dodge, personal communication, 1993; E. Fletcher, personal communication, 1993). For this reason, visiting women on site may be perceived as eroding confidentiality, and many women may find a locally based 'drop in' service preferable.

Continuity of care

If continuity of care is to be an achievable aim, the midwife's role in liaising with other health professionals becomes the more important when clients are moving site on a regular basis. Many authorities have health visitors and social workers who are designated to work with travelling people. Since they cross boundaries that midwives do not, their relationship with the travellers may be more firmly established. Some GPs are also known among travelling people to be sympathetic to their cause (Feder 1990). If this is the case, midwives should not miss opportunities for liaising with them.

It is generally recognised that it takes time to build a relationship with travelling people. The development of trust is unlikely to be facilitated by constant change (E. Fletcher, personal communication, 1993). As midwives tend to work for one health authority, they will have problems maintaining continuity when travellers move around. Where sites are more permanent, however, allocating responsibility for travelling women and their babies to one midwife or a small team of midwives has proved to be successful (L. Dodge, A. Eckford, J. Wilkins, personal communications, 1993).

Communication by health care workers may be facilitated by hand-held notes. Family record cards with information about the GP, social services, vaccinations and immunisations, cervical smear status and any disabilities in the family have been introduced by Batstone (1993) to improve communication. The use of hand-held notes (Feder 1990) has been a positive development in empowering travelling people.

Certain investigations, for example cervical smear tests, may be refused by some clients. Some travelling women find the use of a vaginal speculum

unacceptable. Termination of pregnancy is often seen as an unacceptable option among travelling peoples, so blood tests designed for detecting abnormality may be refused.

Care during pregnancy

Antenatal care may not be valued: booking into a hospital is for the purpose of securing a bed for delivery (Milne 1988). Education by health visitors has improved the uptake of antenatal care and, where this is provided in a friendly setting in which travelling women are accepted, it would appear that uptake is appropriate (J. Wilkins, personal communication, 1993).

If a woman does not keep an antenatal appointment, it is vital that she is not viewed as deviant or 'a defaulter'. She may be travelling. The letter may not have reached her, especially if her site is not a permanent one. She may have received the letter but be unable to read it. If a woman must be contacted, and the appearance of a uniformed midwife might breach confidentiality or cause alarm, it is advisable to contact the health visitor and ask her to make the visit.

Similarly, travelling women may not attend parent education classes. However, this can be carried out to a degree on an individual basis during antenatal appointments.

The birth

Childbirth was traditionally seen as polluting and took place at the edge of the camp (Okely 1983). This view is still held to varying degrees, and most births now appear to take place in hospital. Men do not generally stay with their women during labour (Raper 1986). Some women are extremely frightened by the hospital environment (J. Wilkins, personal communication, 1993); the strangeness and fear that hospitals may engender in this group of women mean that it is particularly important that midwives employ all their skills to help make the experience of childbirth a positive one. Knowledge and understanding will enable the removal of stereotypical images that some midwives may use to make judgements about the different care that women want. These judgements themselves are a factor in the inequality of health provision (Bowler 1993).

For some 'new' travellers, birth in the home situation is considered to be the ideal, and there are instances of midwives undertaking home deliveries in caravans and teepees (Blake & Langford 1988; Dodson 1990). A study undertaken in Avon found that of 82 women, 38 delivered in maternity units in Avon, 3 had home confinements and for the rest no record of their delivery existed owing to travelling (Hawes & Perez 1995).

Generally, the community will respond to the baby's arrival by visiting the hospital in large numbers. Many women, however, wish to return

home as soon as possible. Midwives may have difficulty actually finding their clients if the address given when the woman leaves hospital is that of a temporary site.

Care in the postnatal period

The demands on the woman to look after other children are likely to be high, and it may not be easy for her to rest. The midwife's role in supporting her is as important as for any other postnatal woman, but support is particularly pertinent with some specific areas of maternal and infant health.

Maternal infections, including breast abscesses and vaginal infections, are not uncommon. Stress incontinence and dyspareunia are cited by health visitors as common difficulties. The support, advice and information a midwife gives may reduce this morbidity. This may be through listening to the client, offering advice or referring the woman to other agencies.

The issue of contraception is important. This should never be discussed if others are present – it is more appropriate to ask, 'May I have a word with you?' Different methods of contraception are acceptable to different individuals. Generally, barrier methods are not acceptable to either sex, and natural family planning is rarely practised. The oral contraceptive pill and Depo-Provera are becoming more acceptable to many women, as is the intrauterine contraceptive device. The choice will depend upon the client's motivation towards different methods, although the younger women are certainly likely to discuss contraception in the right setting (Morton 1988).

It is likely that many travelling women have chronic levels of depression (Crout 1987), which may be due in part to the constantly insecure environment in which they live. A midwife who has developed a good rapport with a woman may be able to counsel and support her.

Where infants are bottle fed, a significant role for the midwife is to ensure that the mother is able to reconstitute and store the feeds correctly. Gastrointestinal and oral candida infections are common, demonstrating the need for education about sterilisation of feeding equipment. Heating in poorly insulated caravans may be by Calor gas which causes problems with condensation, and may lead to chest infections. Fear of hypothermia causes some women to overwrap their baby, thereby increasing the risk of sudden infant death. Health education on this issue is vital therefore.

There is a reported higher incidence of genetic conditions among travelling families, often due to intermarriage (Batstone 1993). In 1991, Gordon *et al.* surveyed 203 families in Ireland and found 12 cases of congenital abnormality among 350 children. The abnormalities detected were congenital talipes (3 cases), coarctation of the aorta (1), congenital glaucoma (2), renal abnormalities (2), coeliac disease (2), I-cell disease (1)

and Hurler's syndrome (1). There was a high level of consanguinity among this population, a risk factor also detected by Tyfield *et al.* (1989), who studied phenylketonuria in a Welsh travelling family. However, some groups are now discouraging the marriage of first cousins, which is a positive strategy to prevent such a high level of abnormality occurring (A. Eckford, personal communication, 1993). Travellers will always care for their children – adoption and child abuse appear to be rare.

SUMMARY

During the continuum of childbirth, travelling women will benefit from the support of a midwife they have come to know and trust. Recent changes in the maternity services, and the emphases on continuity of care and accessibility of services, should enable more travelling women to receive this benefit.

Midwives should ensure that they know the specialist professionals (health visitors, local authority officers and social workers) designated to work with travellers in their own area. They should be aware of which GPs in the area are sympathetic towards travellers.

Midwives should be aware of whom to contact if there is an environmental problem with a site they are visiting, and should be familiar with the appropriate strategies to employ if an eviction order is being placed on a site where a pregnant or newly delivered woman is living. Individual MPs, the local authority and the Safe Childbirth for Travellers campaign can all be contacted about issues concerning site provision.

In areas where travellers are seen regularly, midwives could evaluate the way in which midwifery care is provided to travelling women. How is continuity of care achieved? Would it be appropriate to change working patterns so that a small team of midwives is responsible for visiting the women?

A real challenge for midwives is to make themselves as aware as possible of the women's multicultural perspective, to be respectful and non-judgemental, and to seek to provide an appropriate service that will maximise the chances of any individual travelling woman receiving the best possible care. An informed and individual approach may lead to improved access to health care and outcomes for travelling women and their babies. It may lead to midwives acting as catalysts for change at local (and possibly at government) level as they seek to bring about change by active representation of travelling people.

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The hidden abnormality: the birth of a child with a previously undiagnosed handicap

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This chapter was inspired by the personal experience of the birth of a child with an undiagnosed congenital abnormality and by professional experience of supporting women coming to terms with this situation.

The chapter describes what might be considered 'normal psychological responses' to birth, in order to understand more fully the ways in which women and their partners may respond when faced with the birth of a child who does not fulfil their expectations. If the midwife is aware of the possible responses, she is more likely to be able to help, as well as being more likely to help herself to cope with a particularly stressful part of her role.

A POSITIVE VISION OF PARENTHOOD

Pregnancy and childbirth are listed as 'major life events' (Holmes & Rahe 1967) and as peak developmental experiences by psychologists (Rappoport *et al.* 1977). The outcome will therefore have far-reaching effects on all concerned. The birth should be essentially joyous, but it may be marred for several reasons, not least because the baby is abnormal.

Today, in the Western world, women are usually able to choose when to have a baby. Many women have the opportunity to benefit from contraceptive advice, fertility treatment, antenatal screening and, should the fetus not be perfect, the opportunity to terminate the pregnancy. Thus expectations are likely to be very high. Women imagine that they will give birth safely to a live and healthy baby, at the appropriate time.

For a small percentage of women, this dream is shattered when they give birth to a baby who is less than perfect. How parents accept and learn to cope with this new situation can be greatly affected by the professionals, especially midwives, obstetricians and paediatricians.

BEFORE CONCEPTION

The motivation for having a baby has been well documented (Raphael-Leff 1991) and may include attaining adulthood, building a family, passing on one's genes and having someone to love, as well as a response to social and cultural pressures. Or the pregnancy may be unplanned. Once conception has taken place, however, the woman will experience a variety of physical changes and undergo a series of social and emotional adaptations in anticipation of childbirth. Some women will view this as a period of development, others as a time of crisis (Romney 1984). No matter how much the child is wanted, the woman has to become accustomed to the idea of this 'being' sharing her inner space and part of her inner world (Raphael-Leff 1991). Many women will feel that the pregnancy takes over their life and find that they are planning the future for both themselves and the baby.

The family relationships will alter, together with wider social networks, as the woman and her partner anticipate the responsibilities of parenthood. These may be, at the same time, both demanding and joyful, daunting and satisfying (Ball 1987).

Preoccupation with the pregnancy may explain the vivid dreams experienced by many women and why one aspect of such dreams is often the baby's normality. We would do well to remember that different cultures have different definitions of what is 'normal'. The Siriono of Bolivia, for example, nurture babies with congenital talipes equinovarus but regard twins as unnatural (Mead & Newton 1967). The availability of modern screening methods, of termination for fetal abnormality and of techniques to treat the fetus even before birth may well have affected the view of what is 'normal' in our own culture.

MOTHERHOOD MEANS CHANGE

The impending birth of the first child constitutes the greatest life change that most women will ever have experienced (Kitzinger 1994). They have to consider the effect that motherhood will have on their careers and other aspects of their lifestyle. Changes in body shape can profoundly affect a woman's sense of self-worth, especially with regard to how attractive she feels her partner finds her.

Couples who considered their communication to be good prior to conception may find a deterioration following the birth. There may be emotional outbursts, periods of inattention for each other and an inability to support each other as before (Romney 1984; Kitzinger 1994). Relationships must change as individuals move into another phase of their lives. Furthermore, the changing nature of families today means that few women have the support of a larger extended family. Frequently, social support to ease the transition to parenthood is lacking (Raphael-Leff 1991).

Media pictures of motherhood and new babies tend to be glamorised, the negative aspects being ignored or minimised. Foster (1995) brings to our attention an advertisement from a private fertility clinic, which glamorises motherhood as follows:

There is no other perfume like it, the smell of the newborn: a milk scent, warm scent cuddle essence.

As a result, many mothers feel guilty if they find their new baby difficult to bond with (even though the process of 'attachment' is rarely instant or straightforward – for a fuller discussion, see Salariya 1990). They can feel even worse if the changes to their lifestyle seem at first overwhelming. And yet expectations may have been so unrealistic. In the Western world, where most births take place in hospital, many women will only have seen 'newborn' babies as depicted by the media. The babies of friends, seen at home after a little time and several baths (and without the weight of responsibility), will be very different from a newly delivered baby, still unwashed and unwrapped.

FATHERHOOD

The role of the father varies from culture to culture, but fatherhood is a social construction as the man has none of his partner's physical changes to identify him as a parent-to-be (Summersgill 1993). During the pregnancy, however, he will find his own way in which to adapt. A percentage of fathers may even display symptoms of pregnancy (Fawcett 1978; Summersgill 1993). On the other hand, the father's response may be less positive. He will see his partner change, both physically and psychologically, and he is still expected to attend favourably to her needs. He is expected to react supportively and sympathetically when she has mood swings and when she becomes excessively tired and finds difficulty in moving. The father's role requires new skills, but there is little support available to him. Is it any great wonder then that some men find that the increased demands, perhaps in the face of a reduced income, together with other stresses, such as (in some cases) a reduced libido on the part of his partner, all combine to make the prospect of parenting rather more trouble than it is worth?

SIBLINGS

The reaction of older children to a new baby may vary depending on previous preparation, parental attitudes and experiences, as well as the child's age and temperament.

What the child begrudges the unwanted intruder and rival is not only the suckling but all the other signs of maternal care. It feels that it has been dethroned, despoiled, prejudiced in its rights; it casts a jealous hatred upon the new baby and develops a grievance against the faithless mother. (Freud 1933, cited in Raphael-Leff 1991)

The sibling's reaction may be further complicated if the baby is born with a congenital abnormality. The older child has to cope with the burden this places on the parents, both physically and emotionally. He or she is often in danger of becoming the 'forgotten' member of the family, whose need for support goes unheeded (Trause & Irving 1983, cited in Raphael-Leff 1991). Kennedy (1985) noted that the siblings of handicapped children can be bitter over the attention lavished on the disabled child and the accompanying social discomfort, including stares from strangers and teasing or taunting from friends. These children may, therefore, require help and counselling in order to help them cope with their family situation.

UNDETECTED ABNORMALITY

Despite the fact that there are many antenatal investigations available to detect fetal abnormality, still some babies are born with a previously undetected abnormality.

Estimates of the total incidence of congenital abnormalities vary widely depending upon what is regarded as serious enough to include and up to what age the infants surveyed are followed. Many defects may not become apparent until middle or late childhood. On average, however, a congenital abnormality of significance occurs about once in every 30 live and still births; in 25% of these babies there is more than one defect. Minor abnormalities occur in about another 3% of total births. (Johnston 1994, p 153)

GRIEF AND ADJUSTMENT

The period immediately following the birth is crucial. This is often when the parents first learn of their baby's abnormality, and when, by whom and how they are told are all extremely important. Common questions asked at the time of birth are, 'Is it a boy or a girl?', 'How much does it weigh?' and 'Is it all right?' It is the response to this last question that begins the process of realisation and adjustment for the parents.

As discussed earlier, parental hopes and expectations are likely to have been high during the period leading up to the birth. Together, they may have imagined what their child would be like and hoped that it would be healthy, beautiful, bright and loving. There may have been hopes that the child would resolve family discord, enforce wedlock, be the one to carry on

the family name and even be better in every way than the parents. The birth of an imperfect baby takes away all these idealistic hopes, leaving the parents both disappointed and devastated. They will need to grieve for the baby they did not have, as well as come to terms with the one they did have.

The parents will be subject to a vast range of emotions, including bewilderment, disbelief, guilt, shame and humiliation. These are all part of a pattern of adjustment described by Klaus and Kennell (1983), which is effectively a process of mourning and resolution as described by a number of authors (Kubler-Ross 1970; Drotar *et al.* 1975; Romney 1984). Most writers agree that the first stage is one of overwhelming shock in which the sufferer feels helpless and tearful. This can last days, weeks or even months. It is followed by a period of disbelief and denial. The parents have an urge to flee from the situation or awaken from a bad dream. A further stage is one of sadness, anger and anxiety, in which the parents may have long periods of crying and feeling angry with themselves or with the infant, hoping that the baby will die. Some mothers, believing that death is imminent, actively reject the baby in the hope that this will protect them from further pain. The stages do not follow in any logical order. Parents can move on to anger, then back to disbelief, and then on again to attachment and rejection. The pain is inevitable and real.

Over the following few weeks and months, many parents will find a level of equilibrium as the intensity of their emotional reactions and anxiety lessens. Confidence in their ability to care for their child will gradually increase. The fifth and final stage of reaction to the birth of their child is one of reorganisation and adjustment, when the parents attempt to deal with the responsibilities of having a child with a congenital abnormality. They may by now have a more positive long-term acceptance. Mutual support increases in many cases, although, for some, the stress and strain is too much and leads to separation (Drotar *et al.* 1975).

According to Mercer's (1977) description of this grieving process, the parents may also experience a weakened self-identity and feel social stigma in having an abnormal child. The loss of the perfect child they never had, with the associated emotional and financial burdens, may be overwhelming. Parents will often attempt to gain as much information as possible about the defect in order to be able to deal with its reality. Socially, they may redefine themselves in their new role as the parents of a child with an abnormality. These social and cognitive responses described by Mercer are crucial in order to maintain and increase their self-esteem and to continue in society adjusted to their new role as parents.

ATTACHMENT

The terms 'bonding' and 'attachment' have been used over the past two decades to describe the process by which infant and mother become mutu-

ally interactive and aware. The adjustments contributing to this process have been overstated and frequently misinterpreted (Sluckin *et al.* 1983; Salariya 1990).

Kennell *et al.*, who in 1974 put forward the contentious claim that the first 3 days of life can influence the maternal–infant relationship over the course of a full year, later identified certain aspects of congenital abnormality that may affect the attachment of parents to their infants. These are as follows:

- Is the malformation completely correctable or is it non-correctable?
- Is it visible or non-visible?
- Is it life-threatening?
- Will it have an effect on the future development of the child?
- Is it a single or multiple malformation?
- Is it familial?
- Are there other members of the family with a defect?
- Does it affect the central nervous system?
- Does it affect the genitalia?
- Will there be a need for hospitalisation?
- Will repeated visits to the doctor or other agencies be required?

The importance of these aspects in relation to the bonding process was also noted by Romney (1984). However, when Sluckin *et al.* (1983) reviewed maternal attachment to infants with physical or mental abnormalities, they could find no conclusive evidence that there was any difference compared with the attachment to infants with no handicap. They found both mothers who were resentful and rejecting, and mothers who were loving and devoted. Perhaps it would be more helpful to be less concerned with measurement of levels of attachment very early on and be more aware of how far along the adjustment process between shock and acceptance the parent is at the time that the level of attachment is assessed.

THE ROLE OF THE MIDWIFE

The role of the professional may be crucial in determining the outcome in terms of speed of adjustment and subsequent emotional health. Professional caregivers, therefore, need to develop insight into and understanding of the psychological needs of their clients, and will ideally receive the same insight and understanding of their own psychological needs, as caregivers in stressful circumstances, from their colleagues.

Each midwife is personally accountable for her practice and should 'work in a collaborative and co-operative manner with health care professionals and others involved in providing care, and recognise and respect their particular contributions within the care team' (UKCC 1992). 'Each woman

being cared for by a midwife should therefore obtain optimum care, since the midwife is working as a member of a multidisciplinary team where there is mutual understanding, trust, respect and co-operation' (UKCC 1989).

Coping and growing

When a mother is expecting a baby with a known abnormality, the professionals who are involved in her care can be both informed and prepared for the baby's arrival, and to some extent at least will have been able to forewarn the parents. The midwife looking after the mother will be experienced and, ideally, will have already established a relationship with this mother during the pregnancy. However, when a baby with an unexpected abnormality is born, neither the midwife nor the parents are prepared. The shock and disbelief of the parents may also be felt by the midwife. The reactions of the midwife will be watched closely and, according to McCarthy (1984), are remembered clearly by the mother for years after.

Some forms of congenital abnormality, such as a cleft lip, may be obvious to the parents at the time of delivery, in which case they are likely to want immediate information. Other abnormalities may be obvious only to the midwife, so she may have time to examine the baby carefully before approaching the parents. When the midwife has recognised that there is an abnormality, the manner in which this news is conveyed to the parents is very important. Those parents who see their baby's abnormality themselves should be given honest and reliable information to the best of the midwife's knowledge and be reassured that she will ask the paediatrician to come and see the baby and parents to give them more information. The midwife must admit that she does not know about all conditions and so must only tell the parents what she does know and reassure them that she will find out more. This is the beginning of a trusting relationship that will help the parents to trust other health care professionals. Parental disappointment may be displayed in many ways and can be distressing for the midwife involved. She should know that their reaction is normal and encourage them to express their feelings as they go through the various stages of adjustment. This is very important if they are to grow to love and accept their baby (Klaus & Kennell 1982). The role of the midwife, in standing alongside the parents as they express their anger, fear, distress and disappointment, is extremely important. She can help the parents to begin to accept their child. By supporting them, understanding their emotions and being non-judgemental, she can have a positive influence on parental attachment and self-confidence.

Communication

Parents should be told about the abnormality in appropriate terms, and medical jargon should be avoided. The midwife should be present when the doctor discusses the baby's condition in order to clarify any terminology used and to reaffirm what has been said. McMichael (1971) found that most parents wished to be told about their baby's condition as soon as it became apparent. The information must be accurate and up to date, and will need to be repeated and confirmed several times.

Communication is always difficult in times of stress. Shocked parents may resist unpalatable information. Sometimes information is quite consciously 'forgotten' because to remember it is too stressful. Hospitals, special care baby units (SCBUs) and other hostile environments become associated with fear and distress; in such environments, misinformation and confusion abounds.

Using a midwifery model, such as the assessment of needs model (Crichton 1992; Bryar 1995), helps the midwife systematically to address the woman's physical, psychological, spiritual and sociocultural needs. A clear record should be kept of what information and advice has been offered and what care has been given to this woman and baby. Conflicting advice is especially distressing and dangerous in this situation.

Support

The midwife should encourage the parents to see the baby as soon as possible, especially if the baby is ill and requires admission to SCBU or to the neonatal surgical unit (NNSU). Without this, they are liable to have a distorted image of the baby and its condition. If possible, the baby should be examined in front of the parents to highlight its normal features while allowing them to see the problems in relation to the baby as a full person. In this way, the midwife can behave towards the baby as she would any other and demonstrate to the parents that this baby is a person and an individual. The midwife, however, should not try to force attachment in parents who are not ready, as this may only serve to increase the doubt and guilt they may feel.

Midwives are well placed to counsel the parents, to allow them to talk and express their feelings. The midwife will have regular contact with the parents and will often be the one from whom they are most likely to seek advice. Klaus and Kennell (1982) stated that parents should be encouraged to talk in order to avoid becoming overwhelmed. This will enable them to gauge the reality of the situation. The midwife may therefore be the appropriate professional to co-ordinate the multidisciplinary team involved in the care of the baby. Regular meetings should be held involving all members of the team, including the parents, so that everyone is kept up

to date. Parents should be given regular information so that they do not have to ask for it (Lynch 1989). Many aspects of care will involve decision making by the medical staff, but this should involve the parents. Penticuff (1988) stated that parents involved with severely ill babies should have a role in the treatment decisions as they are to live with the consequences for the rest of their lives.

Ethical dilemmas

Parents are considered competent to make these decisions when they are thinking rationally and fully understand their baby's condition and prognosis. However, the midwife should not make rash judgements on the parents' competency when they are emotional and employing defence mechanisms to cope with the crisis. They are still mourning the loss of their ideal child but, even so, may be able to make intelligent and rational decisions regarding their infant's care (Healy *et al.* 1985). By involving the parents in all aspects of such care, the midwife can help them to become confident and learn to accept the baby. It increases their self-esteem and proves they care for and love their baby (Solnit & Stark 1961). Ideally, this should be done at a pace dictated by the parents and not rushed or forced.

Ludman (1989), carried out a study that showed an increased incidence of depression and anxiety among mothers of sick term infants. This was due to a variety of factors, mainly because the mother was unable to carry out her normal caring role, and because of pressure from medical/midwifery staff for her to remain with her child at all times and resulting in further guilt if she did leave her baby, with its consequences for bonding.

Difficult decisions

Some parents may react to the birth of a handicapped child by saying that they cannot care for this baby and that they want it to be taken into residential care. This should be heard, understood and treated seriously. For some parents, such feelings form part of an initial reaction only; when they have learnt more about their baby and have been able to assimilate the information given to them, they will change their minds. However, some parents continue to feel that this is the only option open to them. Caring for this child appears to be more than they can cope with, for whatever reason. They may also have to deal with other factors, such as marital disharmony, sibling rivalry, altered career prospects and financial constraints. Such parents should be helped to talk through their decision and offered compassionate understanding while they try to decide what is best for both them and their child. These are major decisions with long-term consequences, and parents often need time to think carefully

through the issues involved. At this stage, the child may be fostered, thus allowing the parents time to consider their decision.

MOVING ON

At some point, the parents will have to face other people – siblings, grandparents or other relatives and friends. Some parents may feel isolated and reluctant to venture outside or let anyone see the baby. They may feel inadequate, angry and guilty on the one hand, but on the other love the baby because of its helplessness (Solnit & Stark 1961). Midwives can help the parents to face up to this and can explain ways in which they can try to break the news to others. It may help to take the baby out and to be open in explaining the condition to their friends and relatives. This is often very difficult, and the first time can be the most emotional and even embarrassing, but the more people are used to seeing them with the baby, the more acceptable it will be. As the mother and father have benefited by early contact with their baby, so will everyone else.

The parents may agree that involving others in the care of the baby will be helpful. The extended family and friends may provide welcome additional support for the parents. The benefits of sharing are many, but if the mother or father becomes overprotective, the baby will miss opportunities to develop in a more balanced way and may become overdependent and subsequently more insecure. Again, the midwife can highlight ways in which the parents can stimulate the baby and allow normal behaviour patterns to develop. While the midwife's involvement with the parents is only for a relatively short period of time, she is present at a crucial time in the life of the family, one which may have profound effects on the way its members function together in the future, as well as on how they view other health care professionals.

Practical support

Support for this family with a handicapped child will need to continue for many years, so the family should be put in touch with the appropriate authorities as soon after the birth as possible. The midwife can act as co-ordinator between the various professions and other disciplines, and should have a good knowledge of each person's role. The 'Changing Child-birth' Report (Department of Health 1993) has laid down recommendations for professionals when caring for parents whose baby is handicapped.

Before the midwife discharges the care of this family into the community (after 28 days, or longer if the baby is on SCBU or NNSU), she should ensure that the GP, social worker, health visitor and community nursing services are notified. Finances may become a burden to the family if the mother is not able to return to work, or the care of the baby may involve

additional expenses over and above those usually incurred. Here, the midwife can arrange for the parents to see a social worker who will help the family claim any benefits to which they are entitled, and tell them of any charities (such as the Joseph Rowntree Trust) that may help with additional equipment needed for the home. In some areas, there is also a paediatric occupational therapy service, which will assess the needs of the child at home and any adaptations that may be necessary in the future. The midwife is legally responsible up to the 28th day after the birth, but during that time she can actually help the parents in many ways and can be a guide, friend and counsellor.

The parents need to be aware of the sources of support and help, especially in the early days when they are still suffering from shock. The NHS provides medical staff, nurses, midwives, health visitors, social workers, occupational therapists, psychotherapists, physiotherapists, play therapists and many others. There is also help and support from many other sources, including friends, families, lay support groups, self-help groups and the religious community. While the evidence in the literature (Glendinning 1983) suggests that most parents find such contact helpful, the midwife must be sensitive to the needs of parents who find such groups unhelpful and even disturbing. The midwife can help parents best by providing sources of information and contact names and addresses, and even by offering to accompany new parents to such groups. This help from a respected and trusted professional can have positive benefits for the parents and the child, both immediately and in the long term.

Professional support

There is much in the literature about loss and grief and how midwives as professionals can help women and their families to adjust to new situations (Mander 1994; Sherr 1995). To date, however, there is very little about the needs of the professionals who are deeply involved in caring for families at such a difficult time. Midwives will need help and support from their professional colleagues, either in the form of co-counselling or by established informal supportive networks. Time must be made available to care for the carers. Whatever mechanisms are employed to ensure that this help is made available, the need for its existence is beyond question.

Currently, most midwifery services are being run to try to ensure that women benefit from continuity of care, as highlighted in the report by the Maternity Services Select Committee (1992, the Winterton Report). Midwifery teams have been set up in some hospitals and communities, and where possible midwives aim to follow the women through the antenatal, intrapartum and postnatal periods. Such schemes allow midwives to develop closer relationships with the women and their families, but this sometimes does not allow the midwife any space to deal with her own

emotions. Traditional methods of organising care, especially those that involve the allocation of tasks rather than people, provide ample opportunities for midwives to avoid too close an emotional contact. Where there is continuity of carer, support for the midwife assumes greater importance. When a midwife has been involved in the care of a woman and her family in which the outcome was poor, she needs to know that what she is feeling is normal. She may well experience feelings of shock, grief, self-doubt, anger and fear of the future. She may need to review what has happened over and over again in her mind. If the midwife receives good support, she will, after a period of time, put the emotion to one side and begin to reflect upon how she would deal with a similar situation again. She should then be able to accept the experience as one of learning, using it to teach others, retain her self-esteem and make personal progress. Making a record of the episode, how she dealt with it and what she has learned from it would be a valuable addition to the professional portfolio that all midwives are now advised to compile (UKCC 1991). When dealt with positively, such critical incidents are an important part of learning and growing professionally.

Peer support

What support is available to the midwife herself? The first port of call is probably her colleagues. Ideally, she should be able to discuss with them the events that have distressed her and how she feels about them. Thus her management of the case can be reviewed in a non-judgemental way, and she can be reassured that her feelings are normal and should be expressed.

Experienced staff should show those who are less experienced that the display of emotions is acceptable for professionals. Student nurses and midwives are taught about the grieving process in parents, and similarly it should also be acknowledged that professionals themselves sometimes need to grieve. The midwife should be encouraged to talk, as remaining silent will not help her to come to terms with her feelings. Caring for grieving parents can be very demanding, and the midwife directly involved will, where necessary, benefit from some assistance from her colleagues.

Ideally, a trained counsellor within each organisation should be available for both parents and staff alike. However, such a resource is often unavailable, and midwives, together with other health care professionals, try to counsel parents within the limits of their training and often with no emotional back-up. Midwives could actually help each other by listening and understanding, and should be prepared to suggest that a colleague sees a trained counsellor, via the GP, if that midwife is unable to come to terms with her emotional upset. She must not feel stigmatised.

Each midwife has a named supervisor of midwives to whom she can turn for support when faced with a situation that she has either not faced previously or in which she feels she needs help – be it personal or profes-

sional. The supervisor's role is not only to monitor the standards of midwifery practice, but also to be the midwife's guide and counsellor.

The practising midwife has responsibility for her own professional development. This was recognised by, for example, the English National Board on instituting the Framework and Higher Award in April 1992. This involved ten key characteristics that could be used by the midwife to identify her strengths and weaknesses. These not only help a midwife faced with a distressing situation, but would also assist the more experienced midwife to facilitate and assess the development of others (ENB 1990). Continuing education is a vital role in professional development.

SUMMARY

The psychological effects upon the mother, father and family following the birth of a handicapped baby are far reaching and longlasting. The arrival of the baby will affect all aspects of their lives for the foreseeable future.

Delivery of a child with a previously undiagnosed abnormality presents the midwife with a twofold challenge. First, she must support the parents in such a way that they are helped to come to terms with the reality of their situation. Second, and crucial for the first challenge to be met fully, she must accept that her own reactions of shock and devastation are natural, human emotions. The midwife must deal adequately with these, bringing into play all the professional skills at her disposal in order to achieve an equilibrium. Meeting these two challenges will enrich her own professional development, enhancing her ability to offer assistance to the family in their distress and helping them to accept and deal with their new situation.

The following should be remembered:

1. Ensure that you include topics such as counselling skills and coping with loss in the education you undertake in fulfilment of your statutory periodic refreshment requirement.
2. Listen to parents as they explore their initial grief. Do not attempt to give false reassurance, but give clear information when it is requested.
3. Make appropriate use of your supervisor of midwives, and learn to ask your colleagues for support when you need it.

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FURTHER READING

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USEFUL ADDRESSES

Contact a Family
170 Tottenham Court Road
London W1P 0HA Tel: 0171-383 3555
Fax: 0171-383 0259

This organisation has a directory of over 900 support groups and can put families in touch with each other.

The Family Fund
Administered by the Joseph Rowntree Memorial Trust
PO Box 50
York YO1 2ZX Tel: 01904 621115