CHAPTER FOUR

Them and us: poverty, deprivation and maternity care

Jean Davies

This chapter is based on work carried out in an inner city area in the north of England where long-term unemployment rates were high. Through working with some low-income women and their families, it became clear that the cultural impact of deprivation creates a divide between those on wages and those on welfare, between tax-paying professional and recipient – between them and us. This had an impact on how public services, including midwifery, were used. The work was an attempt to address some of these issues in the provision of a service that was effective, by being provided in a way that made it accessible.

There are many levels of economic division – Britain's poor would be considered rich by some living in other parts of the world; nevertheless, they are poor by the standards of the country in which they live, and the disparity between the upper and lower income ranges is increasing (Child Poverty Action Group 1996). Fortunately, unlike in other parts of the world (ICM 1993), mothers are unlikely to die as a result of childbirth, but the children in the lowest economic ranges have perinatal mortality and morbidity rates that are consistently higher than average (DHSS 1980a).

The effect of poverty on childbearing is one of the greatest challenges for midwifery care. While this chapter looks primarily at Britain, the international challenge of the effect of poverty needs to be kept in mind. Of the half a million women who die as a result of pregnancy and childbirth every year, 99 per cent of these deaths occur in developing countries (Downe 1991).

The title of this chapter is used as a way of emphasising that poverty divides not just in economic terms, but also in how social life is experienced. The Department of the Environment funded the Community Midwifery Care Project through inner city funding in Newcastle between 1983 and 1987 in recognition of the fact that special effort was needed to promote a better uptake of maternity care among low-income women (DHSS 1980a). Four midwives worked on the project, the aims of which were to evaluate the effectiveness of giving enhanced midwifery care to

women considered to be at risk because of their socioeconomic circumstances. The evaluation was done by a social scientist, who was funded for the duration of the project.

The work continued in a modified way following the report of the project (Evans 1987); the evaluation showed that it was possible to give appropriate care to women whose economic circumstances place them in a category of risk. This, however, requires a recognition of what the needs actually are. Many of these were illustrated through the evaluation and research that was carried out as a follow-up.

The data for the Community Midwifery Care Project were gathered prospectively from 263 women who booked for maternity care in the course of 1 year. There were two control groups: a concurrent prospective study of women matched from hospital case notes, and a retrospective control of all the women from the study area who had delivered during the year before the project started. Data were collected through semistructured questionnaires, both pre- and postnatal, and also through case note review. Interviews were also taken with the professionals involved.

The four project midwives worked in a team in two areas of the city that were considered to have low-income indicators (DHSS 1980b). They had an average caseload of 60 women each per year. They gave enhanced care, which was defined as a minimum of four home visits, instead of the usual one. At these visits, diet and smoking were discussed, as were feeding and childcare. It was found that information given on a one-to-one basis was well received, and during these home visits many other issues came to light, often resulting in referrals to other agents such as social services departments. The midwives visited the women in hospital if they were admitted antenatally and also when they were in labour. Most of the deliveries were conducted by the labour ward staff, although the project midwives did deliver some women. Postnatal visiting was regular until the 10th day and extended to the 28th day. There was therefore continuity of carer throughout from a named and known midwife who was easy to contact in the community.

The most important aspect of the care was that it was community based and the midwives were easily accessible as in both areas they had local bases. The women attended their GPs and the hospital for antenatal care as usual, and the project midwives were aligned with GPs who worked in the areas. Some families had GPs from farther afield, and for these women the midwives provided a local point of contact. Local parentcraft classes were instigated in both the areas and the number of women who attended these was a reflection of the neighbourhood approach to the work, which not only made them accessible, but, by being focused locally, also made them more acceptable (DHSS 1986) (Table 4.1).

The importance of the work being locally based cannot be emphasised too greatly. As the midwives became familiar figures in the neighbourhood

and through the local base, the number of informal exchanges increased and street 'consultations' were frequent. Early referrals for pregnancy became common as trust developed, and it was not uncommon for someone to stop a midwife on behalf of a neighbour or friend. The classes will be explored more fully below, as it was through these that it was possible to identify some of the particular issues relating to providing care in areas of economic deprivation.

Table 4.1 *Attendance at community-based parentcraft classes (reproduced from Evans 1987)*

Age	*Project women (%)*	*Control women (%)*
<20	38	9.3
20–30	24.6	5.5
>30	22.2	0
Attendance at hospital classes all ages		
All	4	9.8

The results of the work showed not only that women were very satisfied with the enhanced care they received, but that there were also positive clinical trends. Project women who had a previous preterm baby were shown to be less likely to have a subsequent preterm baby than the control women who had received no additional care.

Three-quarters of the project women smoked, but there was evidence that there was a greater reduction of smoking among project women during pregnancy than among control women. There was evidence from the postnatal questionnaires that the project women who received the additional information about nutrition had a greater awareness of nutrition, had improved their diet and maintained the modifications well into the postnatal period. The uptake of family planning and subsequent attendance at child health clinics was shown to be higher among the project women than the controls. Job satisfaction for the midwives was also raised.

THE PARENTCRAFT CLASSES

In one of the areas, the classes were run along traditional lines in the local clinic. The following relates to the other, which was run in a neighbourhood centre. This centre was a joint enterprise, set up by the project midwives and the social services department in order to provide health promotion through an attempt to increase self-awareness, confidence and esteem. The housing department provided a council house on the estate as the city council recognised that there were multivariate problems which it was hoped would be reduced through positive preventative measures.

The classes were hard to establish, as the women did not at first attend. Some of the men did not like it when they did and would come and say the women were needed at home; one man used to come outside the centre and whistle for his wife. Initially, the women were reminded in the morning that there was a class in the afternoon. These were presented more as a get together of those who were pregnant rather than as a class *per se*. It is not uncommon to experience difficulties in setting up classes in areas of high unemployment and low income, and the time involved in establishing them has to be considered if they are to succeed. Once they had been established, they developed their own momentum, as the women still wanted to come after they had had their babies. Out of this grew a children's centre, as the women not only identified the need for a meeting place, but, through the neighbourhood centre, were able to put together a case to the social services department for this to be developed.

The neighbourhood centre provided a non-clinical venue; eventually a steady flow of women attended and the group became known as 'Pregnant in Cowgate'. The aim was to give information about pregnancy, labour and parenting, and also about general health and childcare. The classes were unlike any experienced previously by the midwife who had had many years' experience in teaching antenatal classes. There was one vociferous woman who 'knew it all': she had four children, was having a fifth and would quite cheerfully tell the midwife, who only had three, that she was not as competent to talk about childbearing.

There was blunt realism, sometimes verging on the crude, as tales of events and happenings in the neighbourhood were told. These were considered more immediate than were discussions about babies, and out would pour dire tales the like of which this midwife had never heard; away the group would go on the wild whim of some local story, retold and elaborated, which centred on some activity that was quite often on the other side of the law.

Discussion about issues relating to pregnancy did take place but not in the way in which antenatal classes are usually conducted. It is a challenge to midwives to provide parentcraft education for client groups for whom structured classes are alien. Cornwell (1984) shows that health education is only effective if it changes private perceptions, and when self-esteem is low, health education needs to be given in a way that supports and does not further undermine esteem, and which is accessible, as otherwise it will not be effective. Learning is not likely to happen if there are barriers, and a lot of effort went into reducing the 'them and us' lines through sharing, perhaps a cup of tea or experiences about children. Not being judgemental was vitally important, and this is a large issue as cultural codes, which create the barriers, are not held in common. It was through trying to make sense of these classes that a theoretical framework emerged about some of

the mechanisms that women developed for coping with long-term unemployment and which were a challenge to work with for the midwives.

THEORY

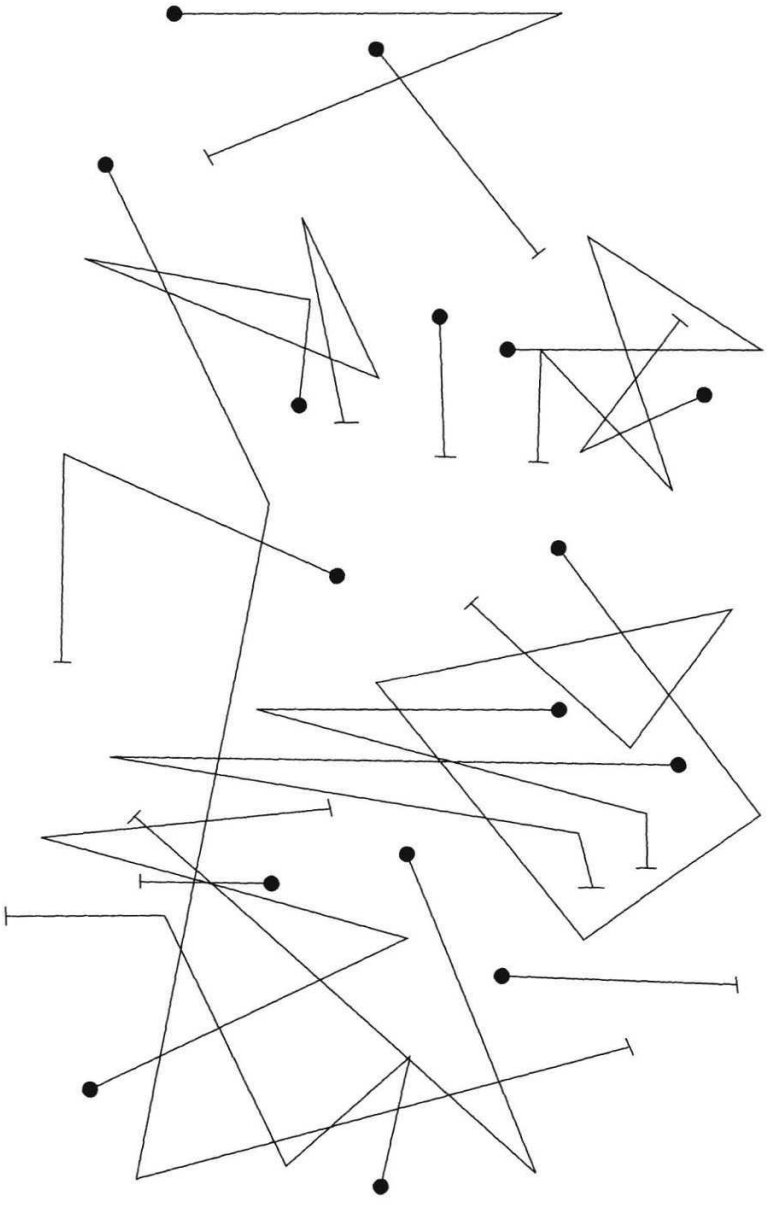
After the midwives had worked in the area, having taught the classes and seen various patterns of behaviour repeating themselves throughout the estate, a theory began to emerge that there were consistencies that could be identified (Glaser & Strauss 1967). The first was that during the group sessions the topic of conversation would jump about from one thing to another, and rarely was one topic developed fully. The second was that the women kept moving house.

The theory developed was referred to as the 'waterboatman theory', describing the phenomenon of flitting about on the surface, and referring to the observation that this appears to be one way in which economically disadvantaged women cope. In order to survive long-term poverty (Jackson 1982), with its debt and despair, women learn to skate along on the surface like waterboatmen. It is better to develop a means of staying on top, which they appear to do by keeping moving, skittering from subject to subject, in any direction, without the intention of or necessarily getting there but with the realisation that if they stopped to consider, or ponder on problems, they would sink. This explained the difficulty experienced when trying to keep to any definite topic during the sessions.

This was not a reflection of competence on the part of the women, but reflected a way of keeping going, of coping. It was quite disconcerting to be discussing, for example, pain relief in labour, to suddenly have the topic moved to the use of drugs for 'recreational' use, and how their use by partners was having an impact on the women. These diversions were frequently dramatic, often recounted entertainingly, but were also disturbing, both in their content and as diversions. They highlighted the divide between an often naive professional who could concentrate, and the worldly, streetwise group of women living very near a variety of very dangerous edges, who would not concentrate for fear of falling.

The theory was supported through a study of 80 women (Davies 1995) using semistructured questionnaires that looked at social activity, experience of health and family networks. This study was a result of questions that were raised by observations made during the project. One observation was made that women frequently moved house; these moves were mapped as the frequency was extraordinary. The maps made a graphic representation of the theory, as they showed patterns of how the women changed course and kept on the move, without actually moving away. There were five mappings carried out on the estate, each with 16 women's house moving drawn. All the maps show similar patterns of movement (Figure 4.1).

Figure 4.1 *The house moves of 16 women on the estate*



House moving was a common activity on the estate. Housing was blamed for many problems and it was thought that, by moving, there was an escape from these. However, underlying problems relating to debt and poverty could only be alleviated for a period, and even this alleviation stopped when the social security payments for house removal and furniture were stopped, and loans were offered instead. When sought, many of these loans were refused because they were only given if there was evidence that they would be repaid. The fact that the moves were repeated indicates that here was an idiosyncratic response to living and being trapped economically. Sixty-five per cent of the occupants had rent arrears in 1989. The housing department had allowed this situation to arise, and the residents were not rehoused in council property off the estate if they owed money, but the council recognised that moving tenants within the estate could reduce some of the tensions that arose, and consequently house moving was common. Around it arose complex issues of supply and demand, control and coercion, sometimes expressed by vandalism. These were issues that were difficult for the locally based housing department officers to deal with. The midwives worked in close liaison with them: the housing department was in the other half of the semidetached building that housed the neighbourhood centre. There was a multidisciplinary task group in which others, such as teachers and probation officers, worked towards a cohesive approach to care in the community. This group formed a forum for discussing the particular constraints that each group had. There were health issues that provided particular challenges to midwives.

Smoking

Seventy-six per cent of the women in the study smoked. During the classes a 'no smoking' period was achieved. It had to be constantly reinforced and was treated at times with derision, the women simply going outside to smoke. However, they came back, although some tried to light up before the allotted period was over, but the directive approach within an overall non-directive session highlighted smoking as an important issue. There was always a lot of discussion about it. Information about babies being smaller if the women smoked during pregnancy was welcomed as a 'good thing' since most women believed that delivering a smaller baby would be easier. There was always also the tale told of so-and-so who smoked 40 a day and produced a nine pounder, which was presented as proof that the midwives did not know what they were talking about.

The view was often expressed that health workers, including midwives, were inadequate innocents who did not have a clue what they were talking about. They obviously lacked street credibility in the harsh world of the inner city where cigarettes were often cited as the 'only pleasure' there was to be had. Notwithstanding this, however, the message about smoking was

reinforced at every contact, often with humour and banter, and the fact that the women continued to attend the group indicated that the ban was not a barrier. It is possible that the tea, the chat and the 'food spot' counteracted the smoking ban. One of the most persistent smokers gave up some time after attending the group; she said it was being told so often about it that made her eventually stop.

Nutrition

Initially, the idea had been to have cooking sessions at the classes, but the kitchen was not safe because there were often children underfoot. Consequently, the midwives brought in food made at home. This was partly to introduce new foods and bring nutrition into the discussion, but it was also important as a social act, reducing the barriers between 'them and us' that prevented views being exchanged and ideas being transmitted. The idea of nettle soup was greeted with horror, but the soup was tasted with interest.

Food is obviously an essential component of health. In the study of 80 women, 53 per cent had not eaten either fruit or vegetables the day before the interview, 37.5 per cent had eaten nothing on the day of the interview and two women had eaten nothing at all the day before the interview. One commented that when she got the shakes she just drank some pop, which made her feel better, along with a cigarette. Two women said that they 'regularly' had a bowel movement only once a fortnight, and eight said it was only once a week; it is difficult for a midwife to stop asking about this even in a research project (Davies 1989).

Self-Esteem

Pregnancy is the ideal time for introducing and developing an awareness of health and the self-esteem that is essential for a positive approach to parenting (Aarvold & Davies 1995). The work that was undertaken in the neighbourhood centre was not only antenatal classes, although these definitely opened the way for some of the women to attend other community development events in the centre. These have evolved, and now there is an active group, organising holidays, children's parties and other activities.

The neighbourhood centre, which was established with the Community Midwifery Care Project and the social services department, had a common philosophy of health promotion through encouraging individual participation. The centre developed, has a local management committee and is now a focus of community development on the estate. With funding support from Save the Children, the work continues under the name of the Community and Family Health Project. Through being involved in the centre, many women have become active in the community and received support from each other, and it has given a focus for activities for the chil-

dren during the school holidays. Above all, some women have been able to gain self-esteem through this involvement.

Experience of health

A meeting was organised by the health authority and the social services department to discuss health on the estate. Noise was an issue, sleep being frequently disturbed by cars being used for 'joy riding' around the estate. Dogs were another problem, identified as being a health hazard: they would empty the contents of dustbins. A period of free spaying was arranged, and dog sterilisation provided a new angle on family planning.

One of the most important issues that emerged was the perceived effect of violence, and the fear of violence, on wellbeing and the ability to be healthy. The fear of burglary made prisons of people's homes, but what also emerged was that there was often fear within the home.

In the study, the 80 women were asked about their perceptions of health: 75 per cent said that they had health problems. However, only 33 per cent of these had a medical component, 66 per cent related to family, finance, housing and education issues. Of the 25 women who felt that their health was suffering because of family problems, the breakdown of concerns is shown in Table 4.2.

Table 4.2 *Health problems attributed to the family situation*

Problem	*No. of women*
Violence	7
Alcohol and drugs	5
Child abuse	4
Divorce	1
Daughters' boyfriends	2
Child's death	1
Family pressure	3
Children disturbed	2

Thirty-three of the women studied (41 per cent) had visited their GP during the week of the interview. Given that 66 per cent of the recorded health problems were not medical matters, it would seem that here is evidence of yet another divide, or gap, between what this group of women perceive as their problems and the ability of those to whom they turn to do anything about them. That expressed health needs cannot be matched with conventional medical provision may be universal to those with low income.

What was clear was that health was perceived as not only relating to medical issues, although the women turned to their GPs. This is a

dilemma, as it is not within the GPs' powers to address some of the issues on which they are consulted, these being social and economic rather than medical issues. As the steps towards primary care (NHS Executive 1996) take place, the question must be raised of whether conventional primary health care is the appropriate way in which to address the issue of health care provision for groups of low-income women, or whether having something that is community- rather than clinic- or practice-based, where there are facilities for active self-development rather than passive treatment, would address the challenge of low-income women more effectively.

CULTURE

There are cultural and lifestyle issues that clearly relate directly to health, both physical and mental. Only 35 per cent of the women were married; another 37.5 per cent were single and cohabiting. In some cases, however, the man and woman claimed state benefit separately as a way of maximising their income. A number of women said that this gave them an economic security that was absent in joint claims, which were often out of their hands.

This separate claiming could put a strain on relationships within the partnership as there was always the fear of being caught or of someone reporting it. This kind of information was always a source of tension within the community, which could erupt if there were any quarrels between neighbours or even within the families themselves. It undermined any sense of family cohesion, and the poor role model for the young boys of fathers who were neither at home nor economically connected reinforced long-term dependence on welfare (Davies 1992).

The women in the study lived very locally, often seeing their mothers daily, and 80 per cent seeing them at least once a week. The men appeared to be marginal to the daily activities of the children, even though they were not in employment. The most frequent female activity reported was collecting children from school, which 69 per cent did at least once a day. Only 14 per cent of the women had any work, that being all part-time, short-term work. One woman cleaned the Magistrates' Court. It gave her a sense of 'justice' that she was working illegally at the court, which she saw as a tool of 'them'. The work was illegal in that she was also claiming benefit, a fairly common activity that was another source of possible community disruption if knowledge about it was used as a weapon in disputes. The men on the estate had similarly low employment rates.

ECONOMIC DIVIDE

A person living on welfare in Britain might be materially better off than someone living in the Third World, but the economic divide within the country is increasing. During the period of the study, this growing division

became visible with the removal of single payments being available for large items that people periodically needed and a loan system introduced. This reduced standards of living as these loans were often refused because of the inability to repay them. Consequently, the goods for which pervasive advertising creates a need were increasingly difficult to obtain. Houses became markedly shabbier in the aftermath of this. The alienation created by the inability to buy what is readily available, but which is urged on all as being essential, seemed to increase the illegal pursuit of these goods. The reappearance in the estate of bedding plants from an adjacent roundabout was a fairly benign manifestation of economic restructuring. There were a considerable number less benignly occupied, and children below the age of legal responsibility were often commandeered into illegal activities. Raising a family in a neighbourhood where this kind of activity was common was very hard for those who wished to eschew this approach.

Long-term unemployment and dependence on welfare are increasingly becoming major political issues as demographic changes in the economic make-up of Britain occur (*Independent* 1993). With the aging population and high unemployment rates, costs are increasing and political reactions about how welfare should be managed increasingly reflect the divide between 'them and us'. At one end of the spectrum are highly paid executives working within private and public enterprises; at the other end are the long-term unemployed on benefits.

CHALLENGES FOR MIDWIVES

When evaluating the Community Midwifery Care Project, Evans (1987) remarked that a number of the women had commented that the midwives were 'one of us'. From a number of standpoints, not least economic, this was not true, although obviously in other areas there were commonalities, in particular the shared experience of children. That some women felt this relationship shows that it is possible for midwives to meet the challenge of being 'with woman'. This does, however, require an effort to break down some of the barriers that professionals sometimes choose to erect as a means of proclaiming their separate status. This is achievable in a variety of ways, one being through providing very local, women-centred care designed to meet the specific needs of a particular group (Department of Health 1993).

One essential aspect of midwifery is accepting the social integrity of individual women and working to establish ways in which this is upheld. This applies to working with women of any cultural background different from the midwife's and demands a need for self-awareness and reflection about the cultural component of being a midwife. If a woman is unsure of her own self-worth, it is doubly important that midwives help her build it. Birth is a crucial time for women, and midwives have a great responsibility,

and challenge, to guide women into motherhood in such a way as to give them worth – for 'them' individually, and for 'us' collectively.

Using a groupwork approach to parentcraft classes created a forum in which midwives helped women's confidence to grow, and where issues of childcare were raised. These included such topics as the importance of play and positive communication with children. If women are to be supported as they become mothers, it is essential to accept who they are in the first instance.

Much of this work is very low key, but this is a time when 'being with' a woman can affect her psychic development, alter the direction of her life and affect her parenting. It is increasingly important for the children of tomorrow's rapidly changing world to have good parenting today. If, by being 'with woman', midwives can reduce the gaps between 'them and us', not in the economic sphere but by enabling women to have self-worth, they will be meeting a great challenge. Midwifery is a challenge in itself, but there is the even greater challenge of showing that in a society where childcare is becoming a political issue, midwives have a crucial role to play in how tomorrow's children are reared. How women experience the 'rite of passage' of becoming a mother can affect that, and it is the midwives' role to be with them during this crucial transition to make it women-centred. It is a challenge to raise an awareness of just how crucial this time is if there is to be a change 'Towards a Healthy Nation' (Royal College of Midwives 1992).

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CHAPTER FIVE

Midwifery care and female genital mutilation

Joanna Hindley and Sarah Montagu

Female genital mutilation (FGM) is a traditional practice thousands of years old that affects an estimated 80 000 000 women and young girls world wide. Until recently, it was referred to by the euphemism 'female circumcision', which underplayed its life-altering and life-threatening sequelae by allowing confusion with male circumcision. Its effects on a woman's sexuality and her experience of pregnancy and childbirth are particularly profound and therefore pose a challenge to the midwives who will care for her.

FGM most commonly occurs in certain parts of Africa and the Middle East. In some communities, as many as 98 per cent of women and girls will be mutilated. However, the increased mobility of world populations due to poverty, war and famine means that FGM will also be encountered in countries in the developed world. In the UK, the Prohibition of Female Circumcision Act, passed in 1985, made the practice illegal; nevertheless, it is still practised secretly in Britain (Black & Debelle 1995).

Several factors, such as the breakdown of traditional societies, advancement in women's status and increased international recognition of women's and children's rights, for example in the UN Convention on the Rights of the Child (1989), have brought about a more open discussion of FGM. This has led to its widespread condemnation as a practice and to campaigns for its eradication. The World Health Organization has taken up the cause and drawn up specific recommendations for action (WHO 1995).

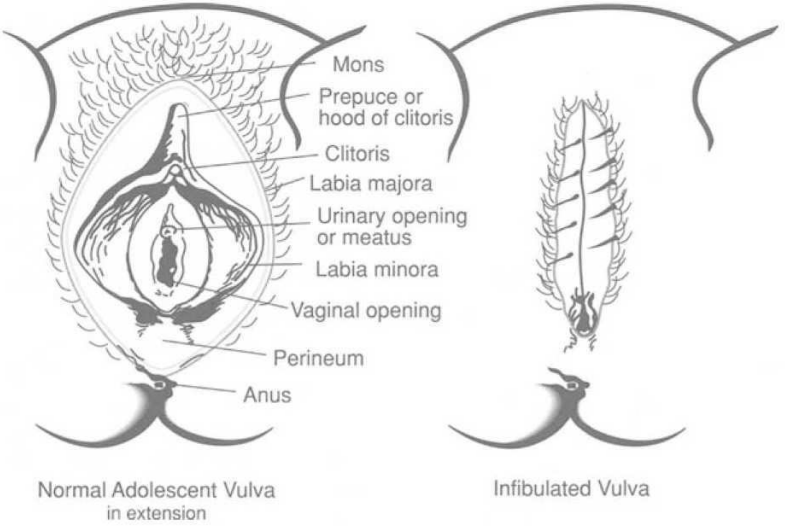
Midwives caring for genitally mutilated women will be challenged to reassess their expectations and practice that have been based on the Western norm of uncircumcised genitalia. They will also need to address issues of racism, ethnocentrism and the status of women in general.

WHAT IS FGM?

It is assumed you are already aware of the anatomy of normal, intact female genitalia and their role and function in female sexuality, pregnancy

and childbirth. In order to provide effective care for women who have been genitally mutilated, you will also need to be aware of the forms of FGM and the anatomical structures affected by each.

Figure 5.1 *Diagrams of intact and infibulated vulva (reproduced with the permission of Minority Rights Group International)*



There are three main forms of female genital mutilation (Figure 5.1):

1. Circumcision – separation/removal of the prepuce (hood of the clitoris).
2. Excision – removal of the clitoris, or removal of the clitoris and all or part of the labia minora.
3. Infibulation or 'pharaonic' circumcision – excision, including removal of the labia majora and suturing together of the raw sides, leaving one very small opening (Dorkenoo & Elworthy 1992).

CULTURAL AND ETHNIC GROUPS WITHIN WHICH FGM IS PRACTISED

In Africa, the belt in which mutilation is commonly practised stretches from Senegal in the west to Egypt in the north east and Tanzania in the south east.

The numbers of women and girls affected may be viewed as percentages of the national population. For example, in Somalia virtually 100 per cent are affected, and in the Sudan, Ethiopia, Mali and Sierra Leone, 90 per cent (Dorkenoo & Elworthy 1992). However, the absolute numbers should not be overlooked; for example, although only 50 per cent of women in Nigeria are affected, as Nigeria is the most populated African country, this accounts for one third of the total estimate of 60–80 million.

Infibulation, the severest form of genital mutilation, is most common in Mali, Sudan, Ethiopia, Somalia and Northern Nigeria. However, FGM is not exclusively an African practice. Excision takes place in the Middle Eastern countries of Oman, South Yemen and the United Arab Emirates (UAE). Circumcision is practised by the Muslim populations of Indonesia and Malaysia, and by some Muslim groups in India, Pakistan and East Africa (Dorkenoo & Elworthy 1992).

FGM is not unknown in the West. Clitoridectomies were performed in the nineteenth and even twentieth centuries by gynaecologists to control allegedly deviant sexual behaviours such as masturbation, hysteria and other so-called female disorders (Passmore-Sanderson 1981).

INTERNATIONAL CONVENTIONS AND NATIONAL LEGISLATION PROHIBITING FGM

In September 1990 the United Nations Convention on the Rights of the Child came into force, bringing FGM into the sphere of International Human Rights Legislation. Article 24(3) of this Convention states that 'States Parties shall take effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children'.

Legislation prohibiting infibulation exists in many African countries, including Sudan, Egypt and Burkina Faso. The Inter-Africa Committee, a non-governmental organisation, is co-ordinating 'grass-roots' activities against FGM from its headquarters in Addis Ababa, Ethiopia. Several religious leaders in Africa have made statements clarifying the position regarding FGM in Islam and Christianity, as it has been mistakenly assumed to be a religious requirement (Al Naggar & Assad 1985).

Many European countries have enacted specific legislation banning FGM, for example Sweden, the Netherlands, Belgium and the UK, where the Prohibition of Female Circumcision Act has been in force since 1985 (Dorkenoo & Elworthy 1992).

The UK's Children Act 1989, Section 47(1) empowers local authorities to investigate if they have 'reasonable cause to suspect that a child who lives, or is found, in their area is suffering, or is likely to suffer, significant harm'. Under the Act, as a last resort, a Prohibitive Steps Order can be made to prevent parents from removing a child in order to carry out a mutilation abroad, or a Care Supervision Order can ultimately be sought, if

there is no better way of protecting a child considered to be at risk of genital mutilation (Hedley & Dorkenoo 1992).

As part of the World Health Organization's efforts to abolish the practice, a multidisciplinary meeting for delegates from UN countries was held in Geneva in July 1995. Its aims were to define the different types of FGM, to assess the impact of such procedures on women's health, to identify areas for further research and to draw up specific recommendations for action (WHO 1995).

REVIEW OF THE LITERATURE

The existing literature on female genital mutilation has done much to bring the issues involved into the public arena and to carry forward the campaign to eradicate harmful traditional practices.

Historically, the campaign against FGM has been clouded by issues of colonialism and attempts to represent FGM as a legitimate cultural practice both within Africa and among emigrant groups (Walker & Parmar 1993). One of the most important developments has therefore been the involvement of African women, who are able to relate the issue of FGM to the status of women in Africa in general and to campaign from within the African community against its continuation (El Saadawi 1980; Thiam 1986). It is particularly important for anyone involved in working with the communities that most commonly practise FGM to read these and similar books in order to understand the relevant issues of culture, tradition and women's and children's rights.

The Pulitzer Prize-winning novelist Alice Walker has written a novel that centres on the theme of FGM and the devastating effect it has on women's lives (Walker 1992). She has also collaborated in the production of a documentary film that has shown both the strength of the traditional forces which would maintain the practice and the progress of the movement towards its eradication (Walker & Parmar 1993). However, although there is general material as well as specific guidelines for workers in the community who may be involved in education or child protection work (Hedley & Dorkenoo 1992), there is little practical advice for health care workers who are faced with giving physical and psychological care to mutilated women.

IMPLICATIONS OF FGM FOR WOMEN

FGM affects every aspect of a woman's sexual and reproductive life. A woman who has undergone mutilation may well have a damaged sense of herself as a woman, particularly if the practice of FGM conflicts with her own beliefs and values. The physical and psychological pain that

persists after FGM can completely destroy a woman's sexual pleasure (El Saadawi 1980).

There are damaging consequences from all forms of FGM but the most severe are associated with infibulation. In some cases, excessive vulval scarring leads to anal or even urethral intercourse taking place. The trauma resulting from intercourse increases the likelihood of infection and the transmission of the human immunodeficiency virus. Repeated infections can lead to internal inflammation and scarring, diminishing the chances of conception and at worst resulting in infertility.

In pregnancy, there are likely to be physical problems resulting from the mutilation, including a greater than normal risk of urinary tract infections and vaginal thrush. Certain of the minor disorders of pregnancy, such as frequency of micturition, increased leucorrhoea and pelvic congestion, will be exacerbated.

Fear and anxiety about possible reactions from health professionals may lead to a reluctance to attend for antenatal care, especially if the woman feels she might be internally examined. She will also be likely to feel apprehensive about the delivery itself and how it will be managed.

Labour and delivery present a number of difficulties for the woman, primarily because the sensations and pain may recall her vulnerability at the initial mutilation and the trauma associated with it. She may find herself once again immobilised, flat on her back, exposed and defenceless, feeling her genitals being touched and viewed by strangers. She may not only have to deal with her own feelings, but may also have to cope with the reactions of midwives unprepared for caring for someone affected by FGM, as the following case history illustrates.

> A young Somali woman living in Cardiff was admitted to the local maternity unit in suspected early labour. 'I was having my first baby. The midwife wanted to examine me to see if I was really in labour or not. She asked me to pull my dress up and part my legs so that she could do this. An expression of horror came over her face when she saw me and she rushed off without saying anything. I felt so afraid and alone. The next thing I knew there were five or six people in white coats all looking at me. I didn't understand what they were saying to each other. The pains were getting worse and nobody was helping me'.

In some cases, it has been found that certain forms of pain relief, for example epidural anaesthesia, are less effective. The pain of mutilation is restimulated and is difficult to alleviate by any of the usual means. Due to health professionals' lack of familiarity with FGM, the woman may find herself subjected to inappropriate interventions and the involvement of greater numbers of midwifery and medical staff than is necessary. The delivery itself will be distressing and painful because it necessitates the

stretching and incision of the tough scar tissue of infibulation. Suturing afterwards may pose further problems for the woman, since if she wishes to be reinfibulated, as some women do, she may meet with opposition if the midwife is aware that this would, in effect, contravene the terms of the Prohibition of Female Circumcision Act 1985.

In the postnatal period, the healing process of the sutured areas may be prolonged due to the impaired regenerative capacity of scar tissue. An anterior episiotomy is likely to be very painful, particularly on passing urine, since it involves densely innervated tissue. Should a woman be reinfibulated, the passage of lochia and postdelivery diuresis will be impaired and will predispose her to infection.

CHALLENGES OF FGM FOR MIDWIFERY PRACTICE

The majority of midwives practising in the developed world have not come across FGM and are not prepared for providing care for a woman affected by it. FGM is not covered within the curricula of most programmes of midwifery education and training. Indeed, in most cases, guidelines for good practice and specific provision have not been developed. Standard midwifery textbooks (e.g. Bennett & Brown 1993; Silverton 1993) make either very brief or no mention of the topic. So, as the following case history indicates, seeing a mutilated woman for the first time can cause appalled confusion.

> A student midwife in a Birmingham maternity unit remembers her shock reaction at seeing the vulva of an infibulated woman and her mystification as to what could have possibly caused this. 'I had never seen anything like it before. There was just nothing there; just skin stretching across where the vulva should have been. I thought she must have had some sort of car accident or something! I went and asked for help but the unit was very busy that day and there was nobody available to help me. I was left to get on as best I could. Looking back on it I think that nobody knew what to do.'

Antenatal care

The main challenges for midwives are to provide sensitive antenatal care, specific preparation for labour and delivery, and appropriate psychological care and counselling. The failure to provide these often leads to unnecessary interventions in labour and delivery, for example bilateral episiotomies or even caesarean sections, as staff are not aware of the more appropriate modes of care.

Many of the obstetric difficulties that can arise when caring for a woman affected by FGM can be obviated by good antenatal preparation and appropriate midwifery care that facilitate the progress of normal labour.

At the booking interview, the midwife needs to be alert to the possibility that women from particular ethnic groups are likely to have undergone genital mutilation. In order to elicit this information, she might ask whether the woman 'has had any special operation when she was young' or whether she has 'been cut'.

Interpreters should be available to translate for women whose first language is not English. Ideally, there should be specific provision for women affected by FGM in the form of a community antenatal clinic catering for their particular needs.

Northwick Park Hospital in Harrow, north London, has set up a specialist clinic offering antenatal care as well as counselling for women with FGM who may wish to undergo deinfibulation in preparation for labour and delivery. They offer deinfibulation with reconstruction of the vulva as far as is possible. This is performed in the second trimester, usually under a general anaesthetic.

In areas where a specific clinic like this is not available, continuity of carer is especially important so that a woman with FGM may build up a trusting relationship with a midwife who is familiar with her particular needs, and can therefore offer sensitive and appropriate care. The midwife can also mobilise other agencies, for example specialist counsellors, and arrange referral for deinfibulation if appropriate.

Guidelines for management of labour and delivery should be discussed with the woman and her partner and with other members of the obstetric and midwifery team, and agreed in advance. An interpreter should be present if required. The midwife plays an important role in ensuring that the woman has access to all the information relevant to her care so that she can make informed decisions.

The midwife should be aware that there is an increased risk of infection in the antenatal period for women who have been infibulated and should therefore give advice on ways of minimising this risk. If infection is suspected, diagnosis may be made more difficult if a high vaginal swab is unobtainable. Treatment may also be complicated by the fact that administration of medication per vaginam may be impossible.

Labour and delivery

The most important contribution the midwife can make to the care of the mutilated woman is to implement true midwifery care, in the sense of being 'with woman'. In no area is this more important than in labour and delivery. If the issues raised by genital mutilation have, for whatever reason, not been addressed during the antenatal period, they must now be confronted.

It may be difficult or impossible to perform vaginal examinations, both for physical reasons and because this may be culturally unacceptable to

the woman. This may hinder both the diagnosis of labour and the assessment of its progress. Emphasis may rather be placed on observation of external signs, such as uterine activity and the length, strength and frequency of contractions, or even more subtle indications, such as the woman's behaviour. Where infibulation is present, recourse to rectal examination may be made to assess cervical dilatation.

Monitoring of fetal condition may be carried out by intermittent auscultation. If continuous electronic fetal monitoring is considered necessary, it may be practical only to monitor externally where infibulation makes application of a fetal scalp electrode impossible. Fetal blood sampling and use of an intrauterine pressure catheter will likewise be precluded.

The midwife must assess the woman's need for pain relief and help her to decide what is most appropriate by considering all options available, including non-pharmacological forms of pain relief. The midwife will need to bear in mind that the psychological components of the experience of pain will be particularly strong for the woman who has been genitally mutilated, and she may need to use some of the counselling techniques described by Adamson (1992). It has already been noted, for example, that the pain relief afforded by epidural anaesthesia may be less effective. Administration of a pudendal block, if required, will be complicated by the presence of infibulation, which can so distort the vulval anatomy that it is impossible to locate the pudendal nerve.

Urinary catheterisation may be difficult, if not impossible, to perform where mutilation has altered the normal anatomy. The midwife therefore needs to be particularly careful to ensure that the woman empties her bladder regularly. Other interventions, such as artificial rupture of membranes or prostaglandin induction of labour, may also prove very difficult.

Where infibulation is present, a medial anterior episiotomy will be necessary to expedite delivery. There is some debate over when this is best performed, but it is usually recommended that it be performed as the baby's head begins to crown so that blood loss may be kept to a minimum. Whether or not infibulation is present, the scarred vulval tissue may be more fragile and prone to tear. The episiotomy must be made carefully, to prevent further damage to the area, particularly the urethra.

Repair: the choices

Repair of an episiotomy or a tear will involve decisions about the extent of repair and reconstruction of the vulva. Simply to suture together the two sides of the incision is, in effect, to reinfibulate the woman, which is illegal under the Prohibition of Female Circumcision Act 1985. Midwifery and obstetric staff may be confronted by the request to perform this type of repair and need to be aware of the relevant legislation. The repair must involve recreating a vulval opening by stitching over each of the raw sides

so they do not appose. The suture material of choice is a polyglycolic acid suture (such as Dexon or Vicryl) as this causes less inflammation and is less likely to fall out before the healing process is sufficiently far advanced for the sides of the vulva not to reappose.

The puerperium

In the postnatal period, vulval as well as possibly perineal healing needs to be observed, and the woman should be advised about hygiene, good nutrition and the use of pelvic floor exercises to promote healing. However, the midwife's role in providing psychological and educational support is as important as it is in giving physical care. Both the woman and her partner will need to come to terms with her body image, which has been altered yet again. They may be offered referral to a specialist counsellor (Adamson 1992).

The midwife should discuss with the women and her partner the appropriate timing for resumption of sexual relations. This will depend on the mode of delivery and the stage of healing of the perineal tissue. She should raise the issue of family planning and should present information on the various methods available, enabling the couple to make an informed choice appropriate to their needs, preferences and cultural requirements.

Child protection issues

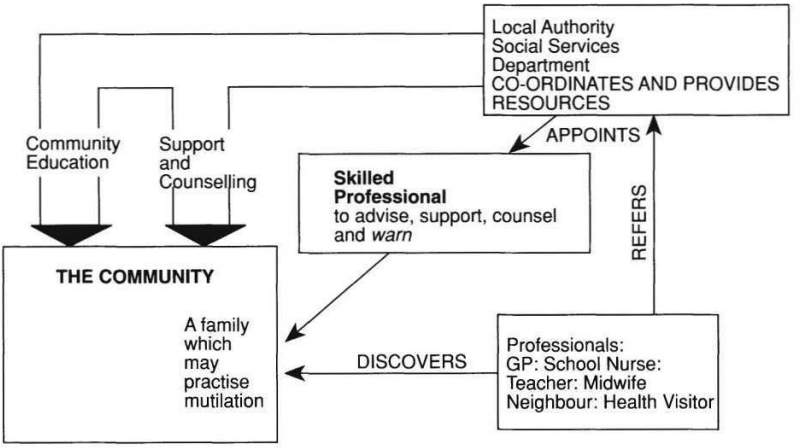
If the child is a girl, the need to protect her against being genitally mutilated should be addressed. It is not too early to mobilise counselling and support to avert potential mutilation. This may need to involve the extended family too, as older family members may put considerable pressure on the new parents to have them conform to tradition (Hedley & Dorkenoo 1992).

Hedley and Dorkenoo (1992) propose a workable system of child protection. They advocate the use of a specialist trained advisor (STA) appointed by the local authority social services department, who may be a midwife, health visitor, social worker or other well-placed professional. The STA will advise, support, counsel and work together with the family to protect the child (Adamson 1992).

Although social services departments have the primary responsibility for ensuring implementation of the child protection system, midwives should make sure that they are included in STA training programmes.

It is estimated that as many as 10 000 girl children in the UK are at risk of genital mutilation (de Silva 1994). Figure 5.2 outlines a proposed child protection system.

Figure 5.2 *A child protection system for FGM (reproduced with the permission of FORWARD UK)*



RECOMMENDATIONS FOR MIDWIFERY PRACTICE

The subject of FGM needs to be adequately covered both within programmes of midwifery education and in standard midwifery textbooks. This would ensure that midwives entering the profession are sufficiently aware of its implications for midwifery practice.

In-service training and study days should be provided for midwives who are already in practice, and the topic of FGM should be included in refresher courses and midwifery update programmes. Guidelines for good practice should be developed and disseminated as widely as possible.

All midwifery units, and certainly those used by a large number of women affected by FGM, should consider making specific provision of care. This should include specially trained midwives, specific antenatal clinics, the availability of interpreters, the provision of specially trained counsellors and the development of channels for referral to specialist centres, for example for deinfibulation.

Links with social services and education departments should be developed in order to co-ordinate action related to child protection and the prevention of FGM.

Practice check

The UKCC Code of Professional Conduct (1993, Clause 7) urges each registered nurse, midwife and health visitor to:

> recognise and respect the uniqueness and dignity of each patient and client, and respond to their need for care, irrespective of their ethnic origin, religious beliefs, personal attributes, the nature of their health problems or any other factor.

With this in mind, ask yourself the following questions:

- How will I feel if confronted with a woman presenting in labour who has undergone FGM?
- Do I feel comfortable with issues relating to sexuality? Do these feelings affect how I might behave towards a woman who has been genitally mutilated?
- What is my attitude towards traditional practices that are prejudicial to health and wellbeing? Is this attitude affected by racism?
- Is my ability to speak out against FGM hindered by a fear of being called racist?
- What provisions are there in my local area for women affected by FGM?
- How shall I go about protecting a young girl when I think she might be at risk of genital mutilation?
- How shall I ensure the privacy of a woman in my care who has been genitally mutilated?
- What am I doing to further my own and others' understanding and awareness of the issues surrounding FGM?

SUMMARY

This chapter has highlighted the main challenges confronting midwives when caring for women who have been genitally mutilated. Perhaps the greatest challenge is for the midwife to develop confidence in her own midwifery skills and to feel that she is competent to deliver physical and psychological care to meet these women's needs despite the serious effects of the mutilation they have suffered.

By encouraging readers to think about their own attitudes, practice and the implications in the context of Clause 7 of the UKCC Code of Professional Conduct, the chapter's intention has been to encourage and enable midwives to prepare themselves to care for women who have been genitally mutilated. It may also be used to form the basis for developing standards of care at a local level.

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Films and videos

Another Form of Abuse 1992 London: FORWARD

Cruel Ritual 1991 London: BBC Enterprises

Warrior Marks 1993 London: Channel Four

USEFUL ADDRESSES

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CHAPTER SIX

Hearing impairment and midwifery care

Jennifer Kelsall

As the key professional, companion and communicator for women during pregnancy and the puerperium, the midwife will sometimes be faced with additional challenges. Where a woman has impaired hearing, or where her baby is born deaf, particular strategies will be needed to ensure that both mother and infant receive the care they deserve. Within this context, midwives' responsibilities cover two distinct areas. First, they must be aware of the possibility of inherited or acquired deafness and ensure that no baby who may be at risk is denied early screening. Second, deaf parents presenting for maternity care must have their deafness and preferred communication method considered and recorded so that such care can be tailored to meet their needs (Kelsall *et al.* 1992).

HEARING IMPAIRMENT IN THE NEWBORN

Congenital deafness: asking the right questions

Many of the implications of caring for the parents of a deaf baby will be similar to those of caring for parents whose baby has any congenital handicap (see Chapter 3). This chapter will concern itself with the specifics of hearing impairment.

Midwives should be aware that 1 in 1000 babies is born with a congenital hearing loss and even today these babies are not always identified. During the antenatal period, midwives are in a key position to identify those babies likely to be born with deficient hearing.

At the antenatal booking interview, *all* women receiving antenatal care should be asked the same simple questions about familial hearing problems. If any member of either parent's family has any history of deafness in childhood – particularly where a hearing aid was employed – there is an increased likelihood of hearing impairment being inherited. If the deafness is known to have been acquired through infection or injury, then it will not be inherited. If the cause of deafness is, however, in any way uncertain or unknown, early screening of the newborn infant should be arranged.

Knowing what questions to ask during pregnancy and ensuring that hearing tests occur after birth will not happen automatically unless specific policies are introduced wherever women receive antenatal care. Antenatal booking forms and computerised booking checklists should always include relevant questions about hearing. Information about the importance of implementing this should be included in all midwifery education programmes.

If a fetus is diagnosed as being at risk of congenital deafness, parents should be given appropriate information and support. Explanation of the available hearing tests involved for their baby, support services and counselling should be available from paediatricians, paediatric audiologists or genetic counsellors. After the birth, it is most important that midwives, paediatricians, GPs and health visitors are all aware that early hearing tests are to be carried out. Good communication links between health professionals are essential if a problem is to be identified. Each unit should have a recognised protocol for arranging early hearing tests, together with suitable counselling and support for parents.

Acquired deafness

Not all hearing impairment in infants is inherited. Some babies can be born deaf or are at risk of becoming deaf soon after birth for other reasons. For example (Robertson 1986):

- babies born to mothers who have had rubella in the first trimester of pregnancy (this is less common in developed countries today with the implementation of mass screening and vaccination programmes);
- babies with any craniofacial abnormalities;
- babies with Down syndrome;
- babies with known brain damage;
- babies who have had hyperbilirubinaemia, that is, if the serum bilirubin exceeds the levels indicated in Table 6.1, the risk being greatest with small babies;
- babies with possible aminoglycoside toxicity, that is, as a result of receiving gentamycin/netilmycin therapy or other antibiotics if administered in very large doses;
- babies in whom cytomegalovirus infection has been detected;
- babies with other viral infections – TORCH screen for toxoplasmosis, rubella, cytomegalovirus, herpes and other viruses;
- all babies who have been nursed in incubators in neonatal units for prolonged periods, as high levels of noise within incubators can affect immature hearing.

Early hearing tests should be arranged for babies to whom any of the above applies, as they will be at increased risk of possible hearing damage.

Table 6.1 *Serum bilirubin levels denoting hyperbilirubinaemia*

Gestation in weeks	*Serum bilirubin (μmol/l)*
28	180
30	210
32	250
34	270
36	290
38	350

Appreciating the impact of infant deafness on parents

While identifying babies who may be at risk of impaired hearing, it is important to be sensitive to the effect that the discovery of potential deafness might have on the parents. Not surprisingly, parents who have hearing loss themselves, even where this is profound, know that they will cope with the problems of deafness in their child. They are likely to mother the baby, love him and communicate with him. Their baby may often learn sign language as its first language. Hearing parents, for whom the soundless world is unmapped territory, are likely to find the news much more difficult to deal with. From the perspective of those who take their own hearing for granted, deafness is a disability that is not understood. As such, parents are likely to perceive it as an enormous handicap and may lack confidence in their ability ever to communicate with their baby.

Parents should be reassured, in the first instance, that they will be able to help their baby. Any baby thrives where it is loved, and the deaf baby must still be loved, cuddled and played with in the same way as any hearing child. The parents must be encouraged to talk to the baby in exactly the same way as they would a hearing child, and the importance of holding the baby close so that he or she can see the parent's face should be explained. In order to learn about communicating and how to lip-read, the hearing-impaired child needs to see the facial expression and speech as it occurs on the lips. Additionally, he or she needs to see language on the lips of the speaker occurring naturally, rather in an artificial, noun-only format. Only after understanding language does language itself develop. This is apparent when one considers any toddler, obviously understanding what is being said but as yet only uttering a few words. That child's understanding of language would be greatly inhibited if he or she had only heard nouns out of context. The same is true of the deaf child, who needs

exposure to ordinary conversation but with the obvious visual element being emphasised.

As the child begins to babble, as all babies do, a hearing aid will amplify any hearing the baby may have and enable it possibly to hear its own voice and begin to make some sense of any noises it hears. Where a baby is profoundly deaf, the parents may wish and should be encouraged to learn sign language and use this alongside speech in order to communicate with the child. Expert guidance from a speech therapist will be needed at this stage.

The midwife must support the parents in the care of their child and understand their anxieties, at the same time emphasising that love, normal mothering, baby talk and conversation are just as important for the deaf baby as for the hearing child. In this way, parents can be helped to provide the best foundation for developing whatever communication method their child's hearing impairment warrants.

MATERNITY CARE FOR HEARING-IMPAIRED PARENTS

The midwife is in a position of particular closeness to women and, where continuity of care is properly organised, has several months in which to develop a supportive and trusting relationship as well as being 'with woman' while she is in labour. Kirkham (1986) sees the midwife as being 'the supporter and sometimes therefore the defender of the woman she cares for in labour' and adds, 'but to achieve this we must really concentrate on the woman and her needs'. The positive influence of support during labour itself has been established (McNiven & Hodnett 1992; Hodnett 1994), as has the identification of isolation in the postnatal period as a risk factor for depression (Holden 1990). Yet many deaf mothers experience frustration and loneliness during pregnancy, birth and the puerperium (Jackson 1990). Postnatal discussion with one woman in Manchester showed up the inadequacies of well-intentioned care. This stimulated an initiative to improve the situation and the development of the Maternity Care for the Deaf project in Manchester. If properly informed, midwives can play a pivotal role in the provision of maternity care that is individually suited to parents with hearing problems (Kelsall 1993; Nolan 1994). Unless midwives rise to this challenge, parents with hearing impairment receive inadequate and inappropriate care.

Establishing a rapport with the woman with hearing impairment

Deafness means isolation in the hearing world (Jackson 1990). Conversation is either missing, muffled or misunderstood. General understanding is difficult, and communication – an essential in all maternity care – is minimal. There is an additional stigma attached to deafness that some-