An Investigation Into The Role Of Parents In The Care Of Hospitalised Children

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Abstract

In this thesis a study of the experiences of the parents of children admitted to a surgical ward in a children's hospital in the North of England is reported. The principal purpose of the study was to examine parents' and nurses' perceptions of their participation in the care of hospitalised children. Although parental participation in the care of hospitalised children has widespread support amongst service users, policy makers and professionals, there have been few attempts to examine parents' experiences of their involvement in care and the development of parental participation has not been thoroughly evaluated. This study was designed to increase understanding of parents' perspective and contribute to evaluation of parental participation in care.

The study design included a review of nursing and medical records and participant observation during nine months of data collection. Twenty four interviews with the parents of children discharged from a surgical ward of a children's hospital and twelve interviews with members of the nursing and medical staff of the study ward were tape-recorded. The interviews with parents were conducted in their own homes during the weeks following the discharge of their child from hospital. Data were collected and analysed concurrently so that emerging themes in the analysis could be explored during further data collection. The data set was subjected to thematic content analysis and data collection continued until new themes were no longer emerging in data analysis.

Although parents welcomed the opportunity to stay with their children and to participate in their care in hospital, they also described unsatisfactory experiences. Some parents believed that their role in hospital went beyond participation in care and that they were an essential part of the hospital work-force. Mothers described expertise that they had developed in the assessment of their own children and the problems that they experienced convincing health professionals of the importance of their observations and assessments. Involvement in the care of children in hospital could be a demanding and stressful experience which resulted in parents feeling that they were themselves in need of care. However, the status of parents in the hospital was ambiguous in that they were neither recognised fully as co-workers nor as co-patients. The study has implications for the planning and delivery of care to children and their families and indicates that parental participation is a policy which needs evaluation. The study also demonstrates the value of qualitative methods in the assessment of satisfaction with services for sick children. Recommendations for the organisation of hospitals, the education of health professionals and research are made.

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CONVENTIONS USED IN TRANSCRIPTIONS OF INTERVIEWS

The punctuation used in the transcription of interviews is intended to reflect as accurately as possible the patterns of speech heard on the tape recording of the interview. The conventions used during transcription are detailed below:

,	Short pause during speech.
.	Pause at the end of a sentence.
...	Extended pause by speaker.
( )	Bracketed speech refers to another speaker talking at the same time
[...]	Passage omitted in quotation

INTRODUCTION

This is a study of the experiences of parents who were involved in the care of their children during admissions to the surgical ward of a children's hospital in the north of England. The study originated from my concern about the development of an important policy in children's nursing, the involvement of parents in the care of their hospitalised children. I qualified as a children's nurse at a time when the involvement of parents in the care of their children in hospital was becoming a widespread policy although there were still areas where parents were only welcomed reluctantly if at all. It was an interesting time to qualify because nurses were exploring how to involve parents in more and more skilled procedures. As well as welcoming the chance to participate in this movement, which involved teaching parents new skills and helping them to take on tasks traditionally considered to be exclusively those of nurses, I also began to think about how this would change the organisation of hospitals and the experience of parents who were involved in care. There was very little evaluation of the involvement of parents in care and it seemed to me that there could be costs as well as benefits to parental participation in care. Some evidence of possible problems was provided in the literature that I reviewed for a small study in which I attempted to examine the degree to which nurses and parents negotiated their roles in children's wards (Callery, 1988). In that study I asked nurses to write about incidents when they had thought that parents had wanted either more or less involvement in their children's care and about how the nurse had responded. Although it was not possible to generalise from this small study, it did suggest that the roles of nurses and parents were not explicitly negotiated.

It was from this background of strong but un-formulated concerns that the present study emerged. The literature did not include parents' descriptions of their experiences and it was to contribute to an understanding of parents' experiences of involvement in the care of their children in hospital that this study was conducted.

Since I began this study there have been important changes in the National Health Service. The roles of purchaser and provider of health care have developed as the internal market has taken effect. Increasing attention has been given to the place of the consumer in health care, with the publication of a Patient's Charter (Department of Health, 1991), since revised and extended (Department of Health, 1995). Assessment of consumer satisfaction has increased in importance in health care services and qualitative methods have been used to give consumers a voice (College of Health, 1994).

The study is presented in the context of these changes. The first chapter is a selective review of literature concerned with consumer satisfaction as well as the parent's role in the care of hospitalised children and is followed by a chapter which details the methodological principles which informed the study and how the study was conducted. There is then a chapter which gives details of the context of the study, which is followed by chapters reporting and considering the findings. Most of the discussion of findings is included in these chapters although there is a final short chapter in which the implications of the study are considered and some recommendations made.

CHAPTER 1: LITERATURE REVIEW

Introduction

This chapter begins with a discussion of the importance attached to the views of users in modern health care systems and problems that have been experienced in finding out users' views about health services. The history of the development of parental involvement in care over the last thirty years is considered and current policy is reviewed. Previous studies of relations between health professionals and parents are examined and models of partnership are discussed. This examination of the literature indicates the background to the investigation and the need for the qualitative study reported.

The importance of consumer satisfaction in health care

The place of the consumer is central to the assessment of quality in health care because it is only the user of the service who has the knowledge that is gained from experiencing the service and so purchasers and providers of health care who wish to have access to this knowledge must find ways of listening to service users. Consumers therefore have an important contribution to make to the development and reform of health care services (Donabedian, 1992).

The introduction of an "internal market" into the National Health Service (Department of Health et al, 1989) has further raised the profile of the concept of consumer of health services in the UK because the reforms imply a need for re-examination of the relationship between practitioners and users in the National Health Service (NHS). The traditional conceptualisation of the user in passive terms as a compliant "patient" is no longer acceptable and more active involvement of users in the commissioning and evaluation of health care is now expected. The emphasis on active participation in health care has particular relevance to the care of hospitalised children where it is considered important to involve families in the care of their children (Department of Health, 1991a; Audit Commission, 1993).

The purchase and use of services continues to be separated in the internal market of the NHS and this means that the provider-consumer relationship has not altered to the cash purchase of services that unqualified free market ideology might imply. One of the ways in which attempts have been made to re-order the relationship between consumer and service was the publication of the Patient's Charter (Department of Health, 1991b) and the subsequent publication of a "comparative performance guide" to hospital and ambulance services (Department of Health, 1994). The rationale for the Charter was to alter the relationship between the consumer and the provider in order to extend choice and to make services more responsive to consumers. It is therefore of fundamental importance to establish what consumers want from health services and the extent to which services satisfy consumer expectations. However, despite the large number of patient satisfaction surveys which have been undertaken important problems of definition and methodology remain (Carr-Hill, 1992).

Who is the consumer?

An important problem of definition is who is meant by the term "consumer" (Blaxter, 1995). In the reformed NHS the consumer could be one of a number of people, including the direct user of the service, the agent who purchases the service on behalf of the patient and the community at large. The person who consults a General Practitioner (GP) and is found to have an inguinal hernia is the direct consumer of the GP's services. However, once the need for surgery is identified, the purchaser of the surgery is not the patient but either the fund-holding GP or the local health authority, who then act as proxy consumer on behalf of the patient. There are also circumstances in which the person most directly involved in care is not the principal beneficiary, for example in the case of the outbreak of a notifiable disease the consumer is not only the individual sufferer but the population who are at risk of the disease. In addition there are services which are the subject of interest from potential consumers (for example maternity services) and of a community concerned for the humanity of treatment of vulnerable groups (for example children's services). Consumers, then can be those who experience health care, those who act as proxy for the patient, the wider community with a shared interest in health care, or potential future patients.

The case of children in hospital

In the case of services for sick children the identification of the consumer is particularly problematic. The child who is admitted to hospital is the person most directly involved in the care. However, the child has not necessarily been involved in the decision to seek treatment and in the case of an infant may not even be aware of what the treatment is. An infant may consume most of the resources associated with the hospitalisation but be unable to participate in the planning and evaluation of care. However, the definition of anybody other than the child as consumer results in potential tensions between the interests of the child and those of the person identified as the consumer. It is possible for parents to have purposes and interests that differ from those of their children, which in extreme cases involves parents abusing or neglecting their children. Whilst parents might well be considered to be consumers on their children's behalf on most occasions, this status must be conditional on the way in which the rights and responsibilities of the parent are discharged. Ultimately the judgement about how a parent exercises responsibility for a child will be a decision for the courts, where the behaviour of the parents can be subjected to legal tests of reasonableness. The Children Act (1989) introduced the concept of "parental responsibility", which incorporates the rights and responsibilities associated with caring for a child as parent and in extreme cases parental responsibility can be transferred from the parents to another agency, for example a local authority. A parent who refuses to consent to reasonable health care on behalf of a child will find the court questioning whether parental responsibility should be removed to another agent. It is clear then, that the community as represented in the legal process is in some circumstances another contender for the title of consumer in addition to both the child and parent.

The conditional status of parents as consumers

Although parents' status as consumer is ultimately conditional on the judgement of the court that parental responsibility has been exercised in a reasonable manner, parents will also be subject to more immediate assessment of their conduct. Assessments of parental behaviour will be frequently made by those involved in the child's care, in order to ensure that the child does not come to harm whilst professionals have responsibility for the child. Thus, the medical and nursing staff who care for a hospitalised child are answerable to parents as consumers on behalf of children but are also judges of parents on behalf of the wider community. In these circumstances parents must be self-conscious consumers, who take into account how others will judge their behaviour and present themselves as morally competent (Darbyshire, 1992). Whilst it is reasonable to consider parents as proxy consumers, who act on behalf of the child in most circumstances, it is important to note the conditional nature of this role.

Consumer or user?

One of the criticisms of the term consumer is that it implies a recipient who is not involved in the production of their own health care (Stacey, 1988). This criticism is particularly pertinent in the case of the parents of hospitalised children, who are often closely involved in the care of their children. Thus, the role of parents as consumers is further complicated by their involvement in the co-production of care for their children. One of the implications is that the terminology of "consumer" is inappropriate in this context and it is therefore more appropriate to describe parents as "users" rather than as "consumers" in order to acknowledge their contribution to care as well as their consumption of services

The history of parental participation in care

In the UK concern generated by the work of influential psychologists such as Bowlby (1953) and the campaigning approach of Robertson (1953a) who published a harrowing film of a child abandoned in a hospital ward led to official investigation and recommendations. The Platt report (Ministry of Health, 1959) argued that the exclusion of parents, in particular mothers, from the lives of hospitalised children was damaging and suggested a series of recommendations for good practice which centred on involving the mother in the life of the child in hospital.

Health services for children can be accused of a very slow response to evidence that the organisation of hospital services was damaging to children's psychological health. Despite the recent comment that "The need to keep children out of hospital because of the emotional stress it causes has been well recognised for the last thirty years." (Audit Commission, 1993) there has been slow progress both in the development of alternatives to hospitalisation and in the humanisation of hospitals . The work of a number of psychologists during the 1940s and 1950s suggested that children's mental health was affected by separation from their families. Young (1992) in a study of the history of the Hospital for Sick Children, Toronto (HSC) commented that the work of Spence (1951), Bowlby (1953), Robertson (1953b) and Prugh, Staub and Sands (1953):

> "demonstrated the beneficial effects of daily visiting and a play programme on the mental health of young children."

In addition

> "Reformers promoted the idea of close involvement of the mother in the child's hospital care and the use of play as a therapeutic tool. But these ideas were slow to be adopted at HSC and elsewhere."

Consumer pressure for change

The care of hospitalised children has therefore been the subject of consumer campaigns for the last thirty years the National Association for the Welfare of Children in Hospital (NAWCH, now re-named Action for Sick Children) was launched soon after the publication of the Platt report. The purpose of NAWCH was to campaign for the humanisation for the care of hospitalised children and specifically for the implementation of the Platt recommendations. Although some health professionals were involved from the early days of NAWCH it can be seen as a form of consumer pressure group, campaigning for changes in the care of children in hospital. It is a mark of the strength of professional resistance and the degree to which hospitals were institutions which could resist pressure from other agencies that NAWCH's impact was limited. This did not deter other groups from attempting to work on behalf of hospitalised children. In 1980 the Consumers' Association published a report concerned with children in hospital and the charity Save the Children Fund published a report criticising the lack of play facilities for children in 1989.

The question of how hospitals organise the care of children has been regarded as a legitimate topic of public debate by consumer groups, although the slow progress in the implementation of the Platt recommendations suggests that consumer pressure was slow to make an impact. Children's nurses have been presented by professional authors as responding to such pressures:

> "Although there are pockets of resistance, paediatric nursing has clearly made major advances over the last thirty years. This has been stimulated by the above reports and by research and anecdotal evidence which has consistently shown that unsupported hospitalisation can cause long term behavioural problems in children."
> (Evans 1992).

However, these claims of responsiveness to research and consumer need are undermined by the length of time that it has taken for change to happen in children's wards. In fact the history of relations between health professionals and the parents of children cared for in hospital does not reflect well on health professionals. It demonstrates a lack of responsiveness to research evidence, disinterest in the wishes of consumers and even a lack of simple humanity in the management of hospitals.

Although current ideas about what is humane in the care of children would suggest that the exclusion of parents from the care of children was inhumane and cruel, it is possible to understand why this happened. It is difficult for us now to understand the fear of infection that existed in the pre-antibiotic era and these fears provided a justification for the exclusion of parents. It is reasonable to argue that the fear of parental infection of the child was irrational but then fear is not reasonable and rational. However sympathy with professionals who worked in the pre-antibiotic era should also be mediated by evidence that parents were not always treated equally. In a historical study of the history of parental involvement in the care of children at the Hospital for Sick Children in Toronto, Young (1992) examined documents including memorandums and annual reports and interviewed doctors and former patients. These sources suggested that class differences shaped attitudes towards families. In Toronto in the 1940s visiting was permitted for the parents of private patients but not on the public wards. It would appear that the social status of private patients could overcome professionals' fear of micro-organisms. Young explained the differential treatment of private and public patients by reference to the difference in social class of nurses and the families of children admitted to the public wards:

> "parents were considered a 'necessary nuisance', so probably a small group, [private patients] similar in social class to the staff was easier to tolerate".
> (Young, 1992)

It is also possible that direct payment for service influenced treatment and that the parents of private patients were treated more favourably than public patients because they were regarded as active consumers rather than as the passive recipients of a public service.

The limited impact of psychological research

In the UK implementation of the Platt proposals was also very slow. Hawthorn (1974) studied the impact of the reforms using an activity sampling technique, which involved non-participant observation of children and nurses throughout the hospital ward day. The study was conducted in 9 wards and a total of 87,934 observations of children and 25,471 observations of nurses were recorded. Hawthorn found that children were observed to be alone and awake for a high percentage of the time, that they were often observed to be miserable and that individual children had contacts with a large number of nurses, so that children did not have a single carer substituting for a mother. It appeared from Hawthorn's work that very limited progress had been made in the intervening 15 years.

What is the explanation for the slow implementation of Platt's report? The report was based on psychological research, its principles were humane and there was sufficient public concern to have led the government to commission and accept the report. In view of the slow progress in other countries with very different health care systems (Young, 1992) the particular structure of the UK National Health Service would not explain the slowness of change. One explanation for the resistance could have been the training of nurses. Hawthorn (1974) suggested that her results indicated a lack of understanding amongst nurses about children's emotional needs and recommended education and training as the solution to the problems that she described in her study. It was not just in the UK that nurses were trained in procedures rather than educated about children's needs: "Most nurses in the 1960s and 1970s were still products of a rigid procedure-orientated training system, and some were not willing to change their practice." (Young, 1992). However, nurses were not the only or even the most powerful professionals involved in the resistance to parental presence: if paediatricians had been committed to encouraging parental involvement on a large scale then it is likely that nurses would not have been able to resist. In some notable cases paediatricians did welcome parents into hospital but these were exceptions rather than the rule. The resistance of professionals to the presence of mothers in hospitals is most convincingly explained by the sociological analysis proposed by Stacey (1970):

> "either the hospital must accept mothers in the ward as part of the hospital, as part of the interior social system, or the hospital finds itself with no clear boundary between the 'inside' and the 'outside' and with 'strangers' present at all times seeing behind the scenes, Goffman's 'backstage'."

The presence of strangers in an institution jealously controlled by professional insiders presented a major obstacle to the acceptance of parental participation in the care of hospitalised children. It is interesting that in the Hospital for Sick Children in Toronto (HSC) it was the transfer of control of decisions about parental visiting from professionals to administrators that preceded change in the regulations: " Eventually, the power to set visiting polices passed from physicians to HSC Administration, and medical and nursing staff bowed to change." (Young, 1992). It is notable that change was more widespread in the UK in the 1980s, at a time when the management of hospitals was reformed and authority began to transfer to general managers in the wake of the Griffiths report (DHSS, 1983).

Sociological studies of children in hospital

While psychological research had driven the demands for change in the way that hospitals treated children, the slow implementation of change provided fertile territory for sociological research. During the 1970s a series of studies were conducted in Swansea and reported in two books (Stacey, Dearden, Pill and Robinson, 1970; Hall and Stacey, 1979). The Swansea studies described the "unintended distress" caused to children by the working practices of hospital staff (Stacey, 1988) and also examined some of the effects of hospitalisation on the children's families. The Swansea studies continued the campaigning tradition of earlier years and one consequence was a joint study between a sociologist and the staff of a ward in Cardiff which involved the establishment of a Care By Parent unit (Sainsbury et al, 1986; Cleary et al 1986; Cleary, 1992). A Care By Parent unit is a ward where the assumption is that the child's family will give most of the care, calling for help from nurses when they feel the need, rather than the traditional distribution of care where nurses undertake all of a child's care. The Cardiff team followed Hawthorn (1974) in using a technique of activity sampling to examine the effects of the scheme. Their summary of findings was that:

> "Children in the care by parent scheme spend less time alone, particularly when they are awake, and cry less. Most of their contacts, and nearly 90% of their interactions are with family members, particularly mothers ... Children without a resident parent, on the other hand, are cared for by an ever-changing series of nurses ... These children sleep more than other groups, which suggests that their environment is unstimulating, and when they wake they are generally alone."
> (Cleary et al, 1986)

Although the patients were described as "children" in the accounts of the Cardiff scheme, it is noteworthy that the "majority of children involved in the scheme have been babies" who by their nature will have required a considerable degree of routine care. Parents therefore had a fairly obvious role in meeting these everyday needs and it is not surprising to find that a large proportion of the time required to care for the patients was "spent in personal care, like bathing, toileting and feeding" (Cleary, 1992:45). Specific units for Care by Parent (CBP) are based on an assumption that a decision can be made about whether or not this is the appropriate form of care for a particular family and the reports of the Cardiff scheme included descriptions of the criteria for admission to the scheme (Cleary, Gray, Hall et al, 1986). Although it is theoretically possible to move between the traditional system and a CBP unit, in practice this happened rarely and so the decision about the level of involvement was in effect a once and for all decision. It is probably for this reason that CBP units are unusual in the UK and parental involvement has developed in a different form with changes to the organisation of care in existing wards rather than the establishment of separate units. The greater extent of CBP units in areas of the USA (Jennings, 1986) can probably be explained by the greater distances that families travel to hospital and the system of financing health care through private insurance, which make it attractive to reduce nursing costs to the families of chronically ill children.

Developments in theories about the welfare of children since the Platt report

Whilst the Platt (Ministry of Health, 1959) recommendations have gained widespread, if sometimes belated support during the last thirty years, the social world has changed in fundamental ways. For example there has been a dramatic increase in the number of marriages ending in divorce: the number of divorces trebled between 1961 and 1971 and more than doubled between 1971 and 1991, despite a fall in the number of marriages (Central Statistical Office, 1995). There have also been changes in patterns of employment since 1959 with a greater proportion of women in paid employment, and mass unemployment has become a structural feature of the UK economy. These and other changes in the conditions in which families care for their children mean that it can be more complicated for mothers to stay in hospital with their children than it was when the Platt committee's recommendations were published.

In addition to the changes in social structure and expectation there has also been debate about both the substance and the implications of the welfare theories which influenced the Platt committee. The changes in emphasis and their influence on the practice of social workers were summarised by Elliott (1991) in a review of the background to the Children Act, 1989:

> "Michael Rutter's critique of Bowlby's original theory of maternal deprivation and Bowlby's own modifications on this theory led social workers to place more importance on the natural family ... The result was that child-care practices

> emphasised the natural family and sometimes failed to assess appropriately the cost to the child. This was a contributing factor in the deaths of children such as Maria Colwell, who was left in an abusing family with tragic consequences. This emphasis on the family sometimes created confusion as to whose needs should be considered when the interests of child and parent conflicted, hence, the need to make a statement in the Children Act of 1989 that the needs of the child shall be 'paramount'."

Although Elliott's review was written with social work in mind, her discussion of the changing views of child care has wider relevance. Child welfare theories at the time of the Platt report placed strong emphasis on the importance of the mother, or mother substitute, whose love Bowlby (1953) suggested was as important for mental health as nutrients for physical health. The empirical basis for Bowlby's theories was studies of children brought up in orphanages and generalisation to a wider population is problematic. In the intervening period the emphasis moved from mother to family and has since moved from the "rights" of parents to the emphasis on "parental responsibility" that is found in the Children Act, 1989. Thus the Platt recommendations have been implemented in a climate of opinion that has changed in substantial ways since the recommendations were first published.

In addition to the changes in theories concerning the family child relationship, the ideology of "community" has become influential in social policy. Elliott reported that

> "This emphasis on community resulted in a continuing drop in the numbers of children in group care and a more creative approach to fostering schemes ... In the decade between 1978 and 1988, the number of children in local authority residential care, voluntary homes, hostels, and special boarding schools dropped from 37,400 in 1978 to 15,000 in 1988, a decline of 60 percent."

Thus great importance is attached to ensuring that children live with families rather than in institutions and there has been an increasing emphasis on maintaining children's normal way of life and a critical attitude to child care which is based in institutions. These influences would tend to add to the pressure for parents to be involved in the care of their children in hospital. However, Elliott also suggested that the current consensus about the importance of parental responsibility is based on differing understandings of purposes:

> "The emphasis on parental responsibility represents an uneasy alliance between conservative political ideology and professional child-care practice. The former sees parental care as cheaper than public care, while the latter, influenced by theories and ideologies outlined above, finds itself in concurrence."

This difference of purpose of public policy and professional practice is also relevant to a consideration of the care of children in hospital. Put rather starkly, the attractions of a potential supply of free labour in the form of mothers to hard pressed hospitals competing in a market-place are obvious. The importance that is placed on parental involvement by health professionals and families has a very different theoretical basis and purpose because it rests on the benefits to the child of continued contact with a parent. However, in practice the distinction between purposes can very easily be blurred.

Changes in the social world of hospitals.

Although change was slow in coming its effect on the social world of the children's hospital ward has been dramatic. Parents have become the norm rather than the exception in children's wards and have become involved in areas of care that were traditionally the exclusive domain of professionals. It has been claimed that:

> "The increasing emphasis on child and family-centred care and on the involvement of parents in the care of their child has had a major impact on the quality of care offered to children and in particular on the role of children's nurses."
> (Audit Commission, 1993).

The claims for an increase in the quality of care are speculative, although it seems reasonable to assume that children will have benefited from the increased involvement of their parents in their care. What is less clear is how parents view these changes in the organisation of care and in particular whether the way in which these changes have been introduced has been responsive to parents views and wishes. These changes of role have been largely uncharted and the major changes in the social world of children's wards have received little attention from researchers.

An example of the complexities of changes in social relations in hospitals was given by Brossat and Pinell's (1990) discussion of the introduction of a new method of care of parenteral nutrition for children in a French hospital. They suggested that there were two phases of change:

> "(a) An introductory phase, in which social innovations are ushered in while institutional rules are by-passed: this produces a re-

> shuffling of relationships between laypeople - in our case, parents - and the various types of professionals, and transforms the former into indispensable co-partners in the treatment process, within the framework of the ward itself (not only at home).
> (b) A restructuring phase taking place when the innovation has already become a rule, if not a routine: the old schema re-emerges, without however being fully restored."

Brossat and Pinell reported changes in the expectations of parents. Concern with the risk of infection meant that parents were excluded from contact with their child, although psychoanalysts engaged in a study of the psychological impact of the treatment were allowed access:

> "Contact with the child, forbidden to a parent, was permitted to a psychoanalyst, who, on these occasions put on the symbolic white coat, and was thus accredited as indispensable (contrary to the dispensable parent)."

The parent was thus constructed as a pathogenic agent, while psychoanalysts were identified as members of the therapeutic staff. However, the status of parents changed when they became involved in giving the treatment to the children at home and their attention was re-constructed as essential to the child's well-being:

> "...parents were (and still are) subject to overt pressure to conform to the social value of parental devotion, as asserted by the doctor or the nurse. And any attempt on the parents' part to obtain a breathing space was liable to be viewed as a failure to fulfil their parental role. Their recourse to the hospital when faced with a situation which they thought they could not handle, was often interpreted by the ward personnel as a lapse of duty. They did, however, charitably deem it to be an absolvable shortcoming in the case of needy families."

The change in parental role resulted in contradictory expectations by the hospital staff;

> "Parents were to conduct themselves as laymen at hospital, but they could still go on performing some medical tasks for their child, tasks delegated to them by the professional worker ... In hospital they were supposed to act as laymen (although enjoying certain privileges); at home, they had to prove themselves skilful in technique."
> (Brossat and Pinell, 1990)

Brossat and Pinell relied on interviews with psycho-analysts who were present in the ward for a different study of the effects of the treatment on the psychological welfare of the children and families. The study should be treated with caution because the data were obtained from outsiders with a limited involvement in the life of the ward. However, Brossat and Pinell's study did raise important points about the relations between parents and hospital. Their discussion of the contradiction between the expectation that parents will contribute skilfully to the care of their children at home but then accept a passive role in hospital echoed the findings of a Canadian study in which semi-structured interviews with six families were analysed using qualitative methods (Robinson, 1985). These families who cared for chronically ill children found that the competence they had developed was a cause of conflict with hospital staff (Robinson, 1985). While Robinson's study suggested a potentially interesting theoretical point, the level of competence of families must have varied widely as they had been caring for their children for between 3 months and 21 years.

Current policy and guidance for purchasers and providers of health care

The Department of Health published a set of guidelines for purchasers and providers of services for children in hospital which stressed both the importance of avoiding hospitalisation wherever possible and family involvement in care during hospitalisations (Department of Health, 1991a). This was followed by an examination of services by the Audit Commission (1993) which identified:

> "principles which should underlie services for sick children:
> - Child and family centred care
> - Specially skilled staff
> - Separate facilities
> - Effective treatments
> - Appropriate hospitalisation
> - Strategic commissioning
> - Special facilities"

"Specially skilled staff" and "separate facilities" are concerned with ensuring that the particular needs of children are recognised in their care, and particularly that children are cared for separately from adults by staff with appropriate training. Although these might seem un-contentious statements of the obvious, a proportion of children continue to be cared for in adult hospital wards, despite the fact that this practice has long been regarded as inappropriate. The question of effective treatments reflects current concerns with auditing the effectiveness of medical interventions. Appropriate hospitalisation concerns the development of home care for children and strategic commissioning deals with the planning of services.

The sections of the report that are of most interest in this discussion are "special facilities" and "child and family centred care". In the section on special facilities the report suggested that such facilities are needed because of the special needs of children. In addition the report argued that:

> "Facilities for parents are equally important as parents are part of their child's care." and suggested that "There are four main problems: lack of separate facilities; insufficient use made of existing separate facilities; poor facilities for adolescents; lack of provision for parents."
> (Audit Commission, 1993:29)

Specific recommendations concerning facilities for parents were made:

> "All hospitals should provide somewhere for parents to stay overnight, wash, make tea or coffee and to sit in privacy. These should be as close as possible to the ward."
> (Audit Commission 1993:35).

Despite the widespread agreement that the involvement of parents in their children's hospitalisation is an important part of services, the facilities available continue to be limited and inadequate in some hospitals.

"Family centred care" is important, the report suggested, because

> "children are part of a family and are dependent on their parents for physical and emotional care and support. Caring for a child means involving parents and siblings ... Close and continuous involvement of a child's family is now a key principle of child and family-centred care."
> (Audit Commission, 1993:3).

However, the report also suggested that problems exist because "clinicians, managers and other staff do not give sufficient attention to the needs of children and their families" as a result of a lack of written policies and management focus and poor communication between staff and families. It would appear that the Audit Commission recognised that parents have not had a voice in the development of services because it sponsored a personal interview survey of 48 families. The families were selected from the membership of voluntary groups for parents of children with asthma or diabetes or Cystic Fibrosis and so the sample was of children with long term illnesses whose experience would predominantly be of children's medical wards. Little detail is given about how the interviews were conducted although the presentation of results in quantitative form would suggest that structured schedules were used. Families appear to have been asked about how their role in care was determined:

> "Over half of the families reported that their involvement in care on the ward had been on the basis of tacit understanding rather than explicit decisions. Some parents resented that their knowledge and experience in relation to their child was sometimes not recognised. ... When asked why they felt that they were included in the care of their child, 68% of parents in the sample gave reasons which can be grouped under the heading of 'providing support and reassurance to the child or continuity of care in a frightening situation,' but 32% said that their role was to substitute for a 'lack of staff'. This may mean that there are indeed shortages of staff, but it could also indicate a lack of clear policies or a failure on the part of the staff to communicate their policies to parents."
> (Audit Commission, 1993:11).

The study provided some evidence of problems in the relations between nurses and parents and in particular suggested that tensions arose between nurses and parents over the recognition of skills and the division of labour between the two groups. However, the grouping of responses to such a complex topic into two categories was of limited use because it meant that only superficial comments could be made about the findings and no conclusions can be drawn from the evidence presented. Therefore the Audit Commission study of parents' views underlined the need for more in-depth approaches to be used in order to understand the perspective of parents.

The Audit Commission suggested that particular skills are required of children's nurses in order to meet both the child's and the family's needs. The exact nature of these skills is not explained in the report but it is suggested that these skills are not always present (Audit Commission, 1993: 17). However, the importance of the changes in the role of children's nurses identified by the report is emphasised in the statement:

> "Nurses are now much more involved in teaching and supporting parents as prime care givers rather than providing the care directly themselves. This has enabled parents to become more competent and confident in caring for their ill child and the child to be discharged home earlier."
> (Audit Commission, 1993:43).

It is clear from the report that the involvement of parents in the care of their children is an important part of the work of children's nurses and likely to become increasingly important. If services are to be developed which are sensitive to the needs of users, a better understanding of parents' views will be necessary to the development of policies for such services. The development of home care services for children will lead to further demands for nurses to organise the care of children co-operatively with families.

The policies of government and local health services continue to be monitored by Action for Sick Children (ASC, the re-named NAWCH) which has identified problems faced by particular groups of parents. Recent work by this group includes a campaign to raise awareness about the costs of visiting children in hospital and a report about the problems faced by ethnic minorities in dealing with child health services (Slater, 1993). In addition ASC is a partner in Caring for Children in the Health Services (CCHS) which includes representatives of the professions and produces reports about how services can be improved. These include publications about the availability of day surgery for children (Thornes, 1991) and an examination of the interfaces between different health services which identified gaps in services experienced by families (Thornes, 1993).

The involvement of parents in the care of their children has become a feature of government policy and pressure group interest as well as a part of the working life of the health professions. However, the relations between nurses and parents are not unproblematic and require closer examination and so the next section of this chapter is concerned with an examination of a selection of studies of parent professional relations.

Studies of parent professional relations

A theme that has been pursued by some authors in the USA has been to explain differences between the level and nature of parental involvement in care in terms of analyses of the characteristics of parents. On the basis of observations and semi-structured interviews with nurses and parents in a hospital in the USA, Knafl, Cavallari & Dixon (1988) suggested that parents fall into 2 idealised categories. Level I parents were:

> "characterised by their overwhelming trust in and relinquishment of control to professionals and their child-centred outlook. Their trust was evidenced by their attitudes and behaviours. They believed that hospital was a safer place than home for their child. They trusted the competency of the nursing staff and believed that the nurses would provide extra attention to their child when parents were not there "
> (Knafl, Cavallari & Dixon ,1988:121)

Level II "parents were distinguished from level I parents by their monitoring of their child's care.":

> "First, their incoming attitude toward the health care system, doctors, and nurses was one of mistrust. They accordingly defined for themselves an advocacy or 'watch-dog' role to assure that errors did not occur."

The authors also suggested that some parents were to be found between these two extremes and described them as a "transitional group". The typology proposed by Knafl et al has similarities with the description of "popular and unpopular" patients (Stockwell, 1972) because both studies sought to explain social behaviours through identification of characteristics. The extent to which the patient or parent is compliant and co-operative is important in both analyses. The search for defining characteristics that provide clear categories of parents has also been pursued by Schepp (1992). Schepp's rationale was to suggest that:

> "Mothers of hospitalized children, as one group of clients, are known to differ from each other in the amount of control they prefer over their children's care as expressed by involvement ... Mothers who prefer more control over their children's care may experience more anxiety and expend more effort coping with their children's hospitalisation when not given control. Likewise, those mothers who prefer less control may experience more anxiety when encouraged to take more control over their children's care."

This reading of the literature led Schepp to investigate the characteristics of 384 mothers from two in-patient settings by administering self-completion questionnaires. This was part of a larger study to test the reliability and validity of a questionnaire about parents' preferences for control during their children's hospitalisations.

Although Schepp claimed that the purpose of the study was to describe the relationships amongst variables rather than to suggest cause and effect relationships, it is implicit in her approach that parents could be categorised by nurses in order to plan the allocation of nursing care time.

Schepp claimed that mothers of younger children, younger mothers and mothers who spent more time in hospital with their children wanted more control over their child's care and suggested that "the characteristics are important clinically because they are useful in identifying mothers who may prefer more control." In summary: Schepp stated "Young mothers of very young children want to provide care to their children." The size of the sample and the methods used do not justify this generalisation and so the recommendations for practice that nursing time should be directed at helping young mothers adjust to the parenting role in hospital and "In contrast, nursing care time may be more importantly directed toward meeting the child's needs when the mother and child are older" are not justified. Schepp suggested that further work should be undertaken to verify these suggestions but there are fundamental problems with the approach that identifies characteristics and builds them into categories that are purported to predict behaviour. Typologies such as that suggested by Knafl et al and the categorisation of mothers suggested by Schepp share the difficulties that have been identified with studies of "popular and unpopular patients". One of these difficulties of such studies is that they rest on an assumption that it is a set of inherent characteristics that explain a person's behaviour and the responses of other people to that person (Kelly and May, 1982). In other words the social context of the relations between people is not considered and so the typologies are excessively deterministic. These studies are therefore of limited use in understanding the complex relations between nurses and parents of hospitalised children. Whilst the behaviours described by Knafl et al may well be evident in children's wards they are not necessarily the product of inherent characteristics of parents. If they were to be then it would be necessary to consider where these characteristics come from: are parents born as level I or II or do they grow into such roles? What is the process which changes mothers' desire to care for their children as they get older?

A more useful approach to the study of relations between parents and nurses has been to examine parents' experience of their children's hospitalisation. Hayes & Knox (1984) interviewed 40 parents of 35 children, 24 of whom had a diagnosis of cancer and 11 had long term disabilities. These unstructured interviews were conducted in a large hospital in Canada and suggested that negotiation of a role in the hospital was an important source of stress to the parents in the study: because there were differences between nurses' and parents' expectations of the role of parent. The majority of Hayes and Knox's sample were parents of children with cancer and so it is not surprising that stress was central to the parents' accounts. The study indicated a lack of understanding amongst nurses about the nature of parents' experiences and Hayes and Knox suggested that improvement of nursing could be achieved through further research into parents' experiences and identified particular topics:

> "What is the nature of the nurse-parent relationship in hospital?
> Why does friction exist in the negotiation between parents and staff and how is it manifested?
> What are the strategies that would decrease parents' stress during the longer admissions of children with chronic health problems?"
> (Hayes & Knox, 1984)

Hayes and Knox's study indicated the importance of giving parents opportunities to explain their experiences in order to develop an understanding of parents' perspectives. Their concentration on the relations between nurses and parents and their concern with the negotiation of these relations demonstrated the complexity of these relations and the importance of context to parents' attitudes and behaviour. This interactionist approach contrasted with the "characteristics" approach used by Schepp (1992), where the problems in relationships were defined as resulting from the inherent characteristics of parents.

Relations between health professionals and the parents of child patients have also been investigated in paediatric outpatient clinics where a "ceremonial order" of the consultation has been described (Strong, 1979). Strong observed and took notes at

1,120 consultations between staff patients and parents over three and a half years. An important element of the report of this study was the analysis of the meaning of parenthood in the consultations. Strong suggested that parents were idealised in the discourse of the clinic:

> "what parents were actually like: whether they really loved a child or not; the degree of competence with which they cared for it; the responsibility which they themselves might bear for a child's condition - none of these were at issue, at least on the surface, and none of them affected the idealised image which parents were granted. Thus, although children were represented by others, all was for the best, since their representatives were very special sorts of people. Matters could hardly be otherwise, for the qualities ascribed to parents were seen as entirely natural in origin; they went with the job. Every mother, just because she was a mother, was an ideal mother, someone who naturally wanted and loved her children and cared for them with a wholly natural competence."
> (Strong, 1979:.40)

Mothers had a special place in the consultation and whilst fathers and grandparents could take a mother's place, they were treated as "substitutes for the real thing" (Strong, 1979:40). The idealisation of the mother in these naturalistic terms provided clear limits to her role in the clinic:

> "In regard to their children they [mothers] were authorities of unblemished character and competence, but as regards medicine and their relationship with staff they were granted no such authority ... Their idealisation as naturally loving and able was counterposed by an equivalent idealisation of their medical ignorance. However much medical knowledge mothers had, or thought they had, they were almost universally treated as technically incompetent. Correspondingly, whatever the actual knowledge or competence of the staff, in practice they both assumed and were granted the mantle of expert."
> (Strong, 1979:70)

The format of roles that applied to consultations was therefore a rigid one, which prescribed the conduct of the consultation, hence its "ceremonial order". The assumption of virtues inherent in mothers did not prevent the medical staff from scrutinising individual mothers and finding some wanting. Two characteristics in particular interested the professionals: whether parents were "intelligent" and "sensible":

> "The most common medical classification of parents was whether they were 'bright' or 'dim'; 'intelligent' or 'unintelligent' ... The other key quality for which doctors searched was how far parents were 'sensible'. Being 'sensible' meant putting things in their proper context; not worrying without cause; not letting one's emotions influence what one reported to doctors; accepting one's fate; and making hard decisions when these had to be made. In other words it meant an active and competent compliance with medical staff. While some mothers, 'worriers', saw problems where there were none, and others tried to overcome the impossible, the ideal parent had a nice balance of involvement and detachment, subordination and concern."
> (Strong, 1979:156)

Parents were expected to behave in certain ways and risked negative assessment of their competence if they did not fulfil the expectations of the professionals. The relationship between doctors and parents in the clinic was described as a partnership and the idealisation of the participants continued in the construction of partnerships:

> "The alliance considered here had three principal features. First, responsibility for the child was treated, not as the sole right or duty of parents, but as in part shared with staff ... Second, just as other aspects of the participants' character were idealised, so too was their commitment to the individual child and thus to the alliance ... Third, as allies who had come together in a common cause, decisions were not imposed but discussed. The allies might have different interests, powers, rights, skills or duties,

> but progress was by agreement and not by force. Such at least were the overt rules."
> (Strong, 1979:100)

The partnership itself was idealised because the "overt rules" could conceal less open and benign relations. For example in a variant of the consultation that Strong called the "bureaucratic format":

> "parents were both excluded and controlled. They might be partners but they were not equals, and the imbalance of power within the bureaucratic format was one of its most striking features. Although parents had some rights to question and to criticise they could use these only within an overall context of medical dominance. The technical authority given to doctors was matched by an equivalent authority to control almost every aspect of the consultations' shape, sequence and timing."
> (Strong, 1979:128)

Strong's study was important because it furthered understanding of relations in an out-patient clinic but there are important differences between clinics and wards which limit the applicability of the study methods and findings to the relations between health professionals and parents in other contexts. For example, relations in out-patient clinics develop in a very different context to a hospital ward and nurses usually have limited involvement in outpatient consultations. The clinic consultation is a meeting between a couple or a few people at most and takes place in a private place at a scheduled time. Relations in the ward occur in a very different context. The numbers of people involved in a single meeting can be much larger if the ward is of an open type and a variety of people will be involved in meetings as shifts change over and workers substitute for colleagues involved in urgent tasks. There is no guarantee of privacy because hospital wards are the place of work of a large number of people as well as the place of treatment of other patients. These differences in context would affect the extent to which the professional could control the relationship. Therefore it would be unwise to extrapolate Strong's work to the world of the ward and to relations between nurses and parents because of the differences in context and professional grouping. However, Strong's analysis suggested concepts that could be explored in a study of parent-nurse relations.

A programme of study at Goldsmiths College in London developed some of the themes identified by Strong. The first of these was a study of relations between the parents of "several" congenitally ill children and health professionals. Baruch (1982) interviewed parents periodically from initial out-patient consultations, through in-patient care and the year following discharge. Members of hospital staff were also interviewed. Baruch concentrated on what he described as "atrocity stories" which were accounts by parents of events where the care of their child had gone wrong in some way. He was not concerned to establish what the events were and whether or not the parents were justified in their criticisms of the care but rather in how the parents described these events. The accounts presented by the parents had common features which Baruch suggested were of interest in themselves because parents' presented themselves as morally competent:

> "The central feature in all the stories I have chosen to analyse is that something has gone wrong. This mishap involves our respondents, one of their children and members of the health professions. With striking uniformity, the stories address the unstated question 'How could you have let this happen to your child?' In other words, our respondents attend to the issue of their appearance as moral persons, competent members and adequate performers. Here, in formulating their accounts, they attain the status of moral adequacy ... the significance of our

> respondents' atrocity stories lies in the way they establish the rationality of their actions and also their own reasonable and moral character. This is accomplished by appeals to standards of the everyday world which parents assume are shared by the interviewer."
> (Baruch, 1982)

The final mention of parents' assumptions that the "standards of the everyday world" being shared by the interviewer is the key to these accounts because it suggests that they were presented to an imagined jury of the normative standards of the everyday world. The accounts would have been shaped by the assumptions on the part of the parents that these standards were shared by the interviewer. The methodological point is that interviews can be influenced by the assumed standards which the interviewee believes that the interviewer brings to the encounter. The protestations of participants can be influenced by the judgement that they believe the everyday world might make about them. If the presentation of moral competence is of concern in interview data it is also of interest in understanding the relations between parents and health professionals. Presumably parents will feel even more need to present themselves to health professionals as morally competent than to sociologists.

The principal result of the Goldsmiths work was a study of consultations in a cardiology out-patient clinic (Silverman, 1987). Silverman tape-recorded 1200 consultations and analysed the discourse engaged in by parents, professionals and sometimes children. The language of the discourse could have important consequences for the outcome of the consultation, for example Silverman suggested that the social construction of children with Downs' syndrome in the cardiology clinic led to differences in the treatment of their cardiac conditions.

> "Using data drawn from audio-recordings of the paediatric cardiology clinic discussed in earlier chapters, it is argued that the 'normal form' consultation involves an attempt by physicians to supplant parents' 'social' discourse by a 'clinical' discourse. A deviant case is provided in clinics attended by parents of Downs Syndrome children with congenital heart disease. Here doctors conspire with parents to supplant a clinical language by a social discourse which depicts the child's present 'enjoyment of life' within an idealised family setting. This 'demedicalized' model of the child allows the doctor to argue effectively against the cardiac catheterization and surgery that would be employed in children without intellectual handicaps."
> (Silverman, 1987:132)

The special context of the out-patient clinic made it convenient for the study of everyday consultations between doctors, patients and parents and Silverman acknowledged that this was why sociologists concentrated their study on this context. Unfortunately it is not possible to transfer the techniques and theories developed in this context directly to the study of children's wards, although the work of Strong, Baruch and Silverman suggests lines of enquiry for studies of parent-professional relations. The influence of their concepts can be seen in a study of relations between parents and nurses conducted by Darbyshire (1992), who described his intention as:

> "to provide an interpretive account and understanding of resident parents' and paediatric nurses' lived experiences"
> (Darbyshire, 1992:29)

Darbyshire interviewed 26 families (26 mothers and 4 fathers), 14 of them were interviewed either individually or as a couple and 16 of whom participated in group interviews. In addition 12 nurses participated in individual interviews and 15 in 4 focus groups and in total 10 months fieldwork was conducted. All the interviews were conducted in hospital during the hospitalisation of the children in the sample. The setting was a 25 bedded general medical ward and a 22 bedded burns and plastic surgery ward in a large Scottish paediatric hospital.

Darbyshire described parents' accounts of living in the hospital with particular reference to the public nature of parenting a child in hospital. Parents felt that nurses were watching the way they cared for children and making judgements about them and they described a loss of autonomy and control and a feeling that there was a 'take-over' by professionals. Darbyshire's analysis included a chapter under the title "The Moral Imperative: being a 'good parent'", which illustrated the relevance of Baruch's discussion of the presentation of morally competent parenthood to relations between nurses and parents in hospital wards. Parents felt a need to present themselves to nurses as morally competent and this was particularly well illustrated by their concerns about disciplining their children in hospital:

> "The ward was a public arena, with what parents believed to be a
> pervasive set of moral assumptions, namely a professional ethic of
> 'correct' child care practices."
> (Darbyshire, 1992:98-99)

Therefore parents felt reluctant to exercise discipline over their children in hospital as they would have done at home because they felt that nurses were watching over them and would disapprove. Darbyshire suggested that this problem had wider significance:

> "Discipline was an issue which revealed wider issues of control
> and power over the child in hospital and of the importance of
> the parent's moral identity."
> (Darbyshire, 1992:101-102)

However, the discussion of discipline also suggests that children were admitted to hospital for long stays, which would be characteristic of a burns ward, which formed part of the study site. A burns injury is also particularly likely to be associated with parental feelings of guilt and fears that others will make judgements about the behaviour of parents. These special circumstances of children with burns suggest that it is necessary to be cautious about suggestions that the data can support wider conclusions about power and control.

The methodological significance of Baruch's (1982) study of "atrocity stories" has not been recognised in the analysis. An example is the analysis of parents' expressions of strong feelings about the importance of being with their children. Darbyshire described the explanations of parents about why they stayed in hospital with their children as indicative of a "primordial relationship between parent and child" (Darbyshire, 1992:75). However, it is possible that these accounts were influenced by the social context of data collection, particularly the focus group of parents who were all living in with their children. The risk that a participant will address her comments to a moral jury will be increased in the group interview where participants are more likely to influence each other and provide socially acceptable accounts of their experiences. The dynamics of groups can also affect the nature of the discussion that occurs in them. In addition the location of interviews in the hospital could also have affected the nature of the responses.

During extended hospitalisations parents described their relations with nurses changing into friendships and they praised nurses who made a particular effort to be sympathetic and:

> "'took the time and trouble' to show concern and to make conversation, who created a safe and non-judgmental space within which parents could gradually take on more of their child's care and who had been with them especially during the 'black times' of their hospitalisation"
> (Darbyshire, 1992: 330).

It seems that the quality of the experiences of parents was dependent on the goodwill of individual nurses who were able and prepared to take extra "time and trouble". The contribution of committed individuals is of great importance to health care of high quality but it is unrealistic to expect such individual commitments to carry the burden of policy aims. The descriptive approach to the discussion of problems in health care has been criticised for paying little attention to policy and assuming that improvement in understanding will lead to improved operation of policy in the real world (Baruch, 1982).

Two smaller studies by nurses in the UK have been published in recent years (Dearmun, 1992; Coyne, 1995). Both suggested that parents would like more information and both suggested that there was little negotiation between nurses and parents about parents' roles in their children's care.

In this section empirical studies of parent professional relations have been reviewed. The final section of the review deals with the development of models of partnership in health care and the extent to which they contribute to an understanding of parent-professional relations.

Models of partnership

Defining partnership relations between service providers and users is a key problem for the NHS in the 1990s. This is true for commissioners of health care services, who have been encouraged to make "local voices" heard (NHS Management Executive, 1992) and for those concerned with providing care packages for clients in the community (Smale, Tuson, Biehal et al, 1993) as well as for providers of hospital services who are expected to be responsive to the needs of users. Attempts have been made to develop models of the family-professional relationship in order to improve understanding of these relations and to provide guidance for practitioners. In this section a model of partnership between nurses and parents of sick children will be discussed and the relevance of models of relations between parents and other professionals and of relations between care agencies and informal carers of the frail elderly will be considered.

"Partnership model of paediatric nursing"

In the UK professional literature there has been an attempt to describe a model of nurse-parent relations, called the "partnership model of paediatric nursing" (Casey, 1988). Its author claimed that:

> "the paediatric nursing model began as an attempt to describe practice. Through discussion and research it is continuing to

> develop into a useful tool ... It is already leading to better use of the nursing process in children's wards and forms the basis of an RSCN curriculum plan."

Evidence is not provided to justify these claims and so their legitimacy cannot be assessed. It is also difficult to know how widespread the use of this "tool" is. However, my personal experience is that children's nurses and tutors often refer to this work. Casey explained that other models of nursing did not reflect her philosophy which she summarised thus:

> "The care of children, well or sick, is best carried out by their families, with varying degrees of assistance from members of a suitably qualified health care team whenever necessary."

This assumption that parents are the best people to care for their own children is the basis for the policy of parental involvement in care. It led Casey to the conclusion that nurses provide technical care which is separate to the everyday care-work of the family:

> "The paediatric nurse complements parental care by doing things for the child, or his parents, to meet the child's needs. This care may take the form of *family care* (the usual care given to meet everyday needs) or it may be *nursing care* (that extra care given in relation to health needs)."

The approach relies on an assumption that a clear distinction can be made between "family care" and "nursing care". The limited explanation of the two terms suggests that Casey was appealing to a common-sense understanding of the differences between family and nursing care. Despite Casey's assumption that the differences between these two forms of care would be immediately obvious to her audience, the division of care into "family" and "nursing" tasks is problematic. In another paper Casey and Mobbs (1988) linked the partnership model with the concept of "self-care" outlined by Orem (1985) and listed the administration of insulin injections as an example of "nursing" care in which the family might wish to participate. The implication was that nurses would be expected to give these injections during the early stages after the diagnosis of diabetes mellitus and that the family would be expected to learn the task and adopt it as part of their family care in the longer term. A limitation of describing the relations between nurses and parents in terms of the tasks that each performs is that the specific context of the task and its meaning for the participants is not acknowledged. The example of the diabetic child who requires insulin injections illustrates these difficulties. It may well be the case that nurses will give the injections during the child's early hospitalisation. However it is almost inevitable that the family will be required to take on this responsibility subsequently: the child will not be in hospital for ever and it would be financially and socially undesirable for the family to remain dependent on a visiting nurse to give the child's injections. Not only would this be prohibitively expensive but it would also provide poor preparation for the independence that the child will be expected to develop as an adult. The inevitability of the family adopting the task is congruent with the assumption of a movement from dependence to independence that is the basis for Orem's concept of self-care. However, not all hospitalised children will follow this trajectory. In some cases parents will learn to perform complex technical tasks which would be assumed to be part of "nursing" care in a common-sense division of tasks but parents will not always want to become more independent. It is possible to envisage circumstances in which the parents of a diabetic child would not wish to give the injections as they had been as part of their normal routine, if for example the child were to undergo surgery or be seriously injured in an accident. The meaning of a task can change as the circumstances within which the task is performed changes and tasks have different meanings for different parents: some will be more confident than others, some will find giving an injection more emotionally demanding than others and so on. By focusing on the division of tasks Casey and Mobbs failed to identify these important factors which affect the relationships between families and professionals. The model is therefore of limited use in understanding the changes in relations between nurses and parents that have resulted from parental involvement.

Orem's concept of self-care has been used by other authors in discussions of children's nursing. In a book intended to illustrate the use of nursing models in children's nursing three of the eleven case studies used Orem's model (While, 1991). One of the studies was concerned with the care of a child with asthma. In his evaluation of Orem's model the author suggested that

> "The role of the nurse in the care of such children is complex, because there are two foci for that care 'the child' and 'the child's parents/family'. The self-care model provides a very satisfactory framework to explore the nurse's role in detail and also to disentangle the complexities of that role."
> (Whiting, 1991:60).

However, Orem's approach is only helpful insofar as the distribution of tasks between a nurse and a willing and competent family is concerned. Once there is conflict of interest between the child and the family the framework is unsatisfactory because the goals of the different partners in the care are not identical, as they must be if Orem's approach is to be appropriate.

One way to determine the nature of relations between families and professionals is to define the family in terms of care of its child. Thus, in the "partnership model of paediatric nursing" Casey (1988) suggested that the relationship with the family should be seen as essentially a functional one determined by the care required by the child. Thus she argued that "The paediatric nurse is concerned with the structure of the family, the relationships within it and the forces affecting it - but only so far as they affect the family's ability to care for the child". The family is not the patient then, but the nurse should be concerned with the functioning of the family insofar as it affects the caring work of the family. Nurses are required to assess the family in similarly functional terms:

> "Assessing the ability of the child and his parents to care also means
> finding out whether the parents can be present, and whether they
> are able to cope with being involved"
> (Casey, 1988).

The relationship between nurses and families in the "partnership model of paediatric nursing" is therefore conceptualised in terms of the division of the care tasks that are required by the child. The partnership that is presented in the model is limited to the division of tasks between family and nurses. Nurses are required to survey the family in order to assess the extent to which the family is able to extend beyond what is described as family (or everyday) care into nursing (or more technical) care. An alternative approach is to consider the family as the subject of nursing care. However, when professionals re-direct their attention from the individual client who faces them to the family of the client, they are faced with the problem of defining the nature of their relationships with both the individual client and the family. Shwenck & Hughes (1983) discussed the family as patient in family medicine and suggested that:

> "There is a strong tradition of care of one person (Patient) by
> another person (physician). The speciality of Family Practice is

> now proposing, with good reason, that the care of many complicated problems (child abuse, rehabilitation of patients with chronic disease, alcoholism and drug abuse, depression, and pregnancy, to name but a few) has a better outcome if a different entity is identified as patient: the family. But to whom, exactly is the physician responsible for the outcome?"

The term "family-centred care" has become one that is widely used in children's nursing in recent years. It has been suggested that the family should be the focus of nursing care by authors in North America (Robinson, 1994) and in the UK (Whyte, 1992). The consideration of the family as the centre of nursing can result from a view that the problems of children are symptoms of wider problems in the family. In a case study of a child who was refusing to go to school Chapman (1991) described how she found that school refusing was a symptom of deeper problems in the family which could be revealed and treated through psychoanalysis. In this view the family is an organism to be treated as the cause of the child's problems.

In an examination of what they called "family interference" in care Robinson and Thorne (1984) suggested that family behaviour is often interpreted as pathological:

> "Thus the literature supports the contention that interfering families are a problem, and suggests that interfering behaviours reflect either characteristics of the disease and/or hospitalization, or alternatively, long-standing family pathology that erupts in the context of a health care crisis."

Robinson and Thorne suggested stages through which relationships between families and health care professionals develop. Initially, families are naive in their trust of the goodwill and competence of the professionals. A stage of disenchantment follows and leads to the subsequent development of a guarded alliance between the family and professionals. Robinson and Thorne (1984) concluded that :

> "Armed with the insight that families can be expected to perceive the illness experience according to criteria that differ from theirs, nurses can identify what the differing assumptions might be in each clinical situation. Assessing such differences in itself transmits the attitude that the family perspective does have value and that family involvement is relevant to quality care."

Rather than viewing the family as the source of the patient's problem and the focus of treatment, Robinson and Thorne were suggesting that professionals should recognise that patients have families who can contribute to their care.

The construction of the family as participant in care and as the subject of care are not mutually exclusive and the manner in which families can both care for the patient and become the focus of intervention will be discussed later in this chapter.

Whyte (1992) described the care of families of children with chronic illnesses and suggested that the change of focus from the child to the family:

> "seems to be a logical extension of the paediatric nursing role, with particular relevance now that ill children are whenever possible cared for at home rather than in hospital."

In these discussions it is often suggested that the use of systems theory provides a framework for family nursing. However, the family nursing literature has not provided satisfactory answers to the problem of to whom the professional is responsible where there is conflict between the interests of different family members. The most extreme example of this is where there is suspicion that the family of the child are actively harming the child. A debate about the ethics of using covert videoing in order to detect attacks by parents on their children in hospital illustrated that the interests of the child and the family are not always consistent and that health professionals must decide whose interests come first (Foreman and Farsides, 1993; Southall and Samuels, 1993).

The concept of partnership with parents is central to The Children Act, 1989 but concerns about the tensions between the interests of the child and those of the parents have led some professionals to challenge the applicability of this concept in some circumstances. A paediatrician's complaint that parents were automatically invited to case conferences to discuss their children illustrated some of the problems involved in partnership:

> "If the case conference exists to discuss reasonable concerns about a child, whose fundamental basis is totally denied by the parents, it is hard to see how the presence of parents can contribute to the planning of the future protection of the child."
> (Skeffington, 1993).

He went on to argue that the participation of parents in case conferences could lead to early disclosure of allegations about sexual abuse of children which would be harmful to the child concerned. In summary Skeffington argued that:

> "Much has been made, quite rightly, of the emphasis in the Children Act on partnership with parents, *where possible*. However, let us not forget that the primary purpose of the Children Act is to ensure that the welfare of the child is regarded as paramount."

Such concerns about the potential differences between the interests of family members must be recognised in a model of the relations between professionals and families.

Models of partnership have been developed by other professionals who work with children and their families which offer different perspectives on the nature of professional/family relations. In the next sections models of partnership with the parents of children with learning difficulties and of relations between social care agencies and carers of the frail elderly will be considered.

Models of partnership in the care of children with learning difficulties

Three ideal types of relationship between professionals and the parents of children with learning difficulties were identified by Cunningham and Davis (1985). The first of these was the "expert" model, where professionals assess and treat a problem.. Secondly, in the "transplant" model professionals plan care and teach the parents how to fulfil the plan, or "transplant" their skills into the parent. Cunningham and Davis suggested a third type of relationship, the "consumer" model, where parents decide on what they want for their children from a range of options. There are useful parallels between each of these types of relationship and the care of children in hospital, although the context differs because these types are were developed to explain long term relationship as children with learning difficulties grow up.

The "expert" model

In the "expert" model of partnership the parents are informed about what is wrong with their child and what treatment is required. The professionals make the decisions about the child and the parental role is passive. The information that is given to the parents is based on the assumption that they need to know that they can place their trust in the professionals, that whilst the parent may not understand the child's problem the professionals do and that when the time is right the professionals will return the child to the parents with the problem solved. This "expert" model described children's hospitalisation before parents were encouraged to stay and to be involved in children's care. The model implies one explanation for the reluctance of professionals to introduce the Platt reforms which is that the reforms were an implicit threat to the power of experts. The model continues to describe aspects of parents' relations with professionals, for example the relationship between parents and surgeon when a child undergoes a surgical procedure: the parent's role is to be passive and to trust the professionals to take control of their child, as illustrated by the signing of a consent form.

The "transplant" model

The "transplant" model of relationship is a development from the "expert" model in which the involvement of families in the care of their children is acknowledged. The family is expected to be involved in caring for their child in a more active way than is the case with the "expert" model, where passivity of the family is assumed. Decisions about the plan of care remain the responsibility of experts but parents are taught how to implement this plan of care. The "transplant" model is the closest of these models to the relationship outlined by Casey and Mobbs (1988). The case of a diabetic child discussed by Casey and Mobbs is an example of the "transplant" model in practice: professionals advise the family on the care that is required for their child who has developed diabetes and teach the family to give insulin injections, so transplanting a skill into the family. It is hoped that this transplanted expertise will not be "rejected" and will grow with the family. The "transplant" model explains the relationship between nurses and parents that is implicit in much of the professional nursing literature. There are accounts of parental involvement in technical aspects of care, such as the care of central venous lines (Pike,1989). The "transplant" model, while not based on the assumptions of passive co-operation by families that underlie the "expert" model, does rest on an assumption that parents are willing recipients of the transplanted skills and that they will use them in accordance with the prescription of the experts. While this is a model of partnership between families and nurses it is a very unequal partnership, in which parents have little opportunity to control the nature and extent of their participation in the care of their children.

The "consumer" model

The "consumer" model was the third type suggested in Cunningham and Davis's (1985:16) discussion of relations between professionals and the parents of children with learning difficulties. This approach:

> "is based upon the assumption that the parent has considerable knowledge of the family needs and resources and that the relationship should share this within a partnership."

Parents choose on behalf of their children from the range of options presented by professionals. In the context of the long term care of children with learning difficulties such a relationship would be consistent with the emphasis of current government policy on parental choice in education. In the context of acute health care for children the "consumer" model is more problematic because of the life threatening and possibly irreversible nature of acute health care choices.

The consumer model constructs the parents as the maker of decisions about the child's care. The question of proxy consent by parents in cardiac surgery illustrates some of the complications of such decision making. Alderson (1990) studied ways in which decisions about cardiac surgery were made. The methods she used were principally qualitative:

> "This book is based on three years of research in two children's heart surgery units. I observed the out-patient clinics, wards, intensive care units, X-ray and other departments, medical and nursing meetings. I interviewed parents in ninety five-families at length, between one and five times, and talked with many other families and staff members. The semi-structured interviews invited parents to give their account of their child's illness and treatment, and how much they were, or could have been informed and involved in medical and nursing decisions."

Alderson found a range of relations between health professionals and parents:

> "At its lowest, proxy consent is a legal nicety. At its highest, parents' proxy consent is an expression of family-centred care, in which families and staff share responsibility to suit each patient, because they believe that shared care and decisions benefit children."
> (Alderson, 1990:43)

The decision about whether a child should undergo surgery to repair a heart defect is not always clear cut, because moral and social considerations influence the decision as well as the technical cardiological assessment. Silverman (1987) found evidence to suggest that children with Downs' syndrome were judged by different criteria to other children and that they were much less likely to be offered surgery. Parents give or withhold consent on behalf of children and so can be seen to be in the role of proxy consumer. However, parents face difficult problems in challenging medical decisions. Some comments suggested that medical staff did not believe that parents could make decisions on behalf of children:

> "One consultant who spent much time informing families said: 'The idea that you can share discussion with parents is nonsense. The imbalance of information is too great. It is a teacher-pupil relationship.'"
> (Alderson, 1990:44)

In a comparison of one case (Mrs Rodin) with other parents Alderson suggested that

> "Parents like Mrs Rodin want consultants to make moral decisions. Others want a greater share in making decisions, but have difficulty in putting their views if discussion is restricted mainly to questions of medical expertise."
> (Alderson, 1990:57)

The consumer model is one that challenges the fundamentals of the relations between professionals and parents: it is inherent in the relationship that parents will have less power than professionals. When the discourse is controlled by professionals it is difficult for parents to present an alternative view based on their own expertise. The social status of the participants in such discussions is not equal and so there are hurdles to be surmounted if parents are to be consumers.

The tension between accepting the demands of parents as consumers and the assertion of expert judgement by professionals is illustrated in Elliott's (1991) case study of Christopher, a child with eczema. Christopher was admitted to hospital after his parents had been treating his skin at home.

> "After two and a half years of [the parents] delivering dependent-care with very little support it was important that the nurse did not completely take over Christopher's care. Rather she had to discuss with his parents those aspects of care with which they wished to have help and tactfully suggest those aspects with which the medical and nursing staff considered that they required aid ... it was more difficult for Christopher's parents to accept their limitations and need for professional guidance." [than other parents who were relieved to have help]
> (Elliott, 1991: 85).

These comments show an interesting tension between different objectives. On the one hand the parents are consumers, who ask for particular help. However, there were also needs which the professionals decided that it was not appropriate for the parents to meet themselves. The model of relationship is a mixture of "consumer" and "expert" with professionals concerned about how to wrest control from parents in some areas of care without offending the parents or undermining their confidence as carers. The discussion reflects the theme of parental control which recurs in the literature, with professionals both concerned to ensure that nurses are not overly interventionist and do not take over the care of the child but with an implicit concern about how to ensure that parents accept the judgement of experts.

The application of the "consumer" model is limited by the legal framework within which decisions about the welfare of children are made. The Children Act, 1989 states that the interests of the child must be the "paramount" consideration. In addition it introduced the concept of "parental responsibility", in order to change the emphasis on parents as having rights over a child to an emphasis on the exercise of responsibilities. This change in emphasis was to establish the principle that parental decisions about children are limited by law: parents cannot decide to withhold treatment from children without good reason. Before the Children Act, 1989 the courts would have been likely to make the child a ward of court in such circumstances, this might still be the case, or alternatively "parental responsibility" could be transferred away from the parents to another agency. The parent as consumer has limited choices, then, and is subject to regulation by the wider society in the exercise of the rights and responsibilities to make decisions about the health care of her child.

Each of the ideal types of "expert", "transplant" and "consumer" outlined by Cunningham and Davis (1985) explains aspects of relations between families and health professionals when a child is in hospital. However, none of them fully explains family-professional relations and in particular this typology does not account for the twin roles of parents as carers and clients, which are examined in models of relations between social care agencies and informal carers.

Models of relations between care agencies and informal carers

An interesting comparison can be made between parent-professional relations in the care of hospitalised children and the relations between social care agencies and carers for the frail elderly. There are similarities between the care of children in hospital by their parents and the care of the elderly frail in their homes by informal carers: in both cases lay carers provide care with varying degrees of supervision from professional carers. Comparison of how these two groups of lay carers relate to the professional carers with whom they work can provide useful insights into the relations between nurses and the parents of hospitalised children.

Twigg (1989) suggested that "Carers occupy an ambiguous position within the social care system ... the relationship between carers and social care agencies is an uncertain, ill-defined one". She went on to outline three models of the ways that agencies conceptualise carers: carers as resources, carers as co-workers and carers as co-clients.

Carers as resources

Because the informal sector is the predominant source of care for the elderly frail, Twigg suggested that carers are seen by agencies as the "'given', the taken-for-granted reality against which services are structured." Thus services are designed around the assumption that informal carers will provide care. Twigg went on to suggest that the resource of informal carers differs in important ways from the formal sector. Informal care is of lower normative status: the contribution of informal carers is not regarded as of equal status with that of the formal sector. The contribution of informal carers also differs from the formal sector in that the formal laws of supply and demand do not operate. Twigg suggested that this makes informal carers an "uncommandable" resource, because "the pattern of availability of informal carers remains in any extensive sense beyond the influence of agencies." In addition, Twigg pointed out the care provided by informal carers is "undirectable" because "carers are not subject to supervision or control" and so the standards of care provided by informal carers cannot be controlled by social agencies.

The contribution of parents to the care of their children in hospital could also come to be taken for granted and seen as the 'given' around which services are planned. Concern that parental participation in the care of hospitalised children could lead to reductions in staffing levels because the contribution of parents is taken for granted has been expressed by a number of nursing authors (Evans, 1992, Strachan, 1992, Robbins, 1991). The introduction of the Project 2000 form of training is one factor that has reduced the numbers of "pairs of hands" on hospital wards (Elkan, Hillman and Robinson, 1994) and considerations which increase the pressure to maximise the contribution of the work-force could lead to an assumption that parents will fill this gap. There are also parallels between the informal care of the elderly and the care of hospitalised children in the normative status ascribed to different forms of care. Parental care is cast as the continuation of everyday care and distinguished from the technical care provided by nurses in the "partnership model of paediatric nursing"

(Casey, 1988) and a similar distinction was made by nurses and parents in studies conducted by Darbyshire (1992) and Dearmun (1992).

The problem of "uncommandability" of carers applies to hospitals that care for sick children as well as to social care agencies concerned with the elderly: the participation of parents in their children's care is voluntary and so the hospital has little control over this supply of labour. Similarly, parents are informal carers in hospitals because they are not subject to the terms and conditions that apply to formal employees and so their labour is to some extent "undirectable". However, there are important differences between the parents of hospitalised children and informal carers in the home. Hospitals cannot determine whether or not parents will participate in the care of their children but there are potentially powerful moral pressures to conform to the role of morally competent parent (Strong, 1979; Darbyshire, 1992). In addition the work of parents in hospital is much more visible than that of informal carers in their own homes. Supervision is therefore possible, although this does raise the intriguing question of how professionals would go about the delicate task of criticising the standards of care provided by parents to their own children.

Carers as co-workers

In the second ideal type outlined by Twigg (1989) carers are viewed as co-workers, in which "agencies work in parallel with the informal sector, aiming at a co-operative and enabling role." Twigg suggested that problems arise with this model because of the differences between formal and informal care. The formal sector is:

> "universalistic in approach, affectively neutral, and governed by rules of procedure and accountability ... It rests on a formal knowledge base, in which professionals are trained, and acquire particular technical skills." [Whereas the informal sector] "is particularistic, marked by strong affect, frequently characterised ... by effectively inalienable relationships".
> (Twigg, 1989)

These same characteristics distinguish between nurses and the parents of hospitalised children as well as between formal and informal carers for the elderly frail. Twigg argued that "it is because of these essential differences that the two systems do not mesh easily or happily together." It is not clear whether there are similar problems in the care of hospitalised children but the similarities between the two care systems and the need to mesh together suggest that the question is an important one. The construction of parents as co-workers was implied by Casey (1988) in her discussion of the "partnership model of paediatric nursing" when she suggested that nurses should assess family structures and relationships as far as these affect the care of the child. The assessment was concerned with the extent to which the family could contribute to the child's care and so is essentially an assessment of the parents as co-workers.

Carers as co-clients

The third model of carer proposed by Twigg (1989) was the carer as co-client. This applies particularly to the most heavily stressed carers, for whom the burden of caring is greatest. In this model agencies view the carer as a client and "the aim of intervention in terms of this framework is the relief of carer strain; the concept of strain is sometimes here reinterpreted in terms of a medical model of stress."

This model is similar to the approach of "family nursing" advocated by Whyte (1992) and Robinson (1994). The work of caring for the elderly person or the hospitalised child is seen as a stressful load and the intervention of professionals is concerned with helping the carer to cope with this load. This model presents agencies with the problem of assessing carers and deciding where to direct the resources available to support carers. Twigg (1989) graphically summarised the dilemma when she suggested that "to regard carers as co-clients, therefore, threatens, on the one side, an imperialistic take-over of what are normal processes of life; and on the other, a swamping of the social care system with 'ordinary misery'".

Summary

The involvement of parents in the lives of their hospitalised children has developed slowly since concerns were voiced about the effects of separation of child and parent. Psychological research had limited impact and was followed by a number of sociological studies of children's hospitalisation. There is now widespread acceptance of the principle of parental involvement in the professional literature and in official reports and a vocal pressure group continues to monitor the provision of services to children. Existing models of nurse-parent relations are unsatisfactory, although features of relations can be explained by a model of the relations between professionals and the parents of children with learning difficulties. A comparison with the relations between care agencies and informal carers of the frail elderly provides a potentially useful framework for considering relations between nurses and the parents of hospitalised children. Problems have been identified in nurse-parent relations, although there has been limited study of the subject and there are conceptual and methodological problems in those studies. The assessment of consumer satisfaction has burgeoned in recent years although there are problems in the definition of the terms "consumer" and "satisfaction" and there are strong grounds for using qualitative methods in such studies.

There is a need for further study of relations between the parents of hospitalised children and nurses which is based on the experiences and perspective of parents. The most promising approach to such study is to use qualitative methods to provide opportunities for parents to identify their own concerns.

CHAPTER 2: METHODOLOGICAL PRINCIPLES OF THE STUDY

Introduction

In this chapter the methodological principles which informed the design and execution of the study are outlined. Symbolic interactionism, which was the theoretical framework within which the study was designed, is described and ethnographic methodology is discussed. The development of the main study design through preliminary work is described and the methods of data collection and analysis are explained. Discussion of methodological issues and selected texts is included alongside the description of the methods used in order to explain how methodological decisions were made.

Aims of the study

The study arose out of a concern about the impact on parents of their involvement in the care of their hospitalised children. There has been inadequate evaluation of this major change in the hospital care of children, particularly from the point of view of the parents. The purpose of the study was to describe the experiences of a group of parents who had been involved in the care of their hospitalised children and to explore their responses. The aim of this exploration was to understand the views of a group of parents and of the nurses who cared for their children, and to develop an analysis both interesting in its own right and useful to health professionals, families and managers involved in the provision of services for children. During the review of the literature the case of parents of hospitalised children was compared with Twigg's (1989) analysis of relations between care agencies and informal carers of the elderly frail. This comparison suggested useful questions about the relations between nurses and the parents of hospitalised children which the study was designed to explore:

- has parental participation in care become so much the norm that it is taken-for-granted as a resource available to the hospital?
- how does the hospital deal with the problems of the "uncommandability" and "undirectability" of parents as a workforce?
- how do the different knowledge bases of parents and professionals mesh together?
- to what extent do parents become clients themselves?

Selection of theoretical framework

Analysis of how users evaluate health care services has suggested that factors which influence lay evaluation of care can include the goals of the help seeker, their previous experiences of health care, the values of the health care system and lay images of health (Calnan, 1988). The evaluation of services by users is therefore far more complex than the widely used term "consumer satisfaction" would suggest. Examinations of children's wards are further complicated by a social environment where mothers, fathers and health professionals can all participate in the work of caring for children. A single set of criteria with wide applicability that could form the basis for a consumer satisfaction questionnaire would be likely to lack sensitivity to these complexities. Therefore it was decided to place parents' own assessments of their experiences at the heart of the study by using ethnographic methods, based on the framework of symbolic interactionism.

Symbolic interactionism

Symbolic interactionism is based on the premises that "human beings act toward things on the basis of the meanings that the things have for them", that "the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows" and that "these meanings are handled in and modified through, an interpretive process" (Blumer, 1969:2). Symbolic interactionism therefore stresses the construction of meanings through interaction and suggests that these meanings influence behaviour. The interpretation of symbols, whether verbal or non verbal, is an important component in the establishment of meaning and the communication of expectations. The approach is concerned with the minutiae of everyday communication and the examination of the "taken-for-granted" world.

Symbolic interactionism developed from Mead's (1934) approach to anthropology and what became known as the Chicago school of social investigation and theory. The principles were further developed by Blumer (1969), whose work has been highly influential on the development of ethnographic and other qualitative approaches to social investigation.

The aim of symbolic interactionist investigation is to understand how participants in the social world attach meaning to events and the effect that such meanings have on their behaviour. The methods of enquiry are based on the principle of letting the participants speak so that the task of the investigator is to interpret the participant's view of the social world. Where users' evaluations of services are sought, symbolic interactionism provides a framework that stresses the user's own criteria for evaluation. This approach is particularly appropriate to the study of parental participation because this is a complex subject about which little is known. It is therefore more appropriate to generate hypotheses from data than to attempt to test hypotheses which have little applicability because they have been formed on the basis of a currently limited understanding. In addition a hypothesis testing approach is based on the assumption that meaning is what Blumer described as a "neutral link" between a variable and its effect, whereas symbolic interactionism draws attention to the mediating effect of meaning on cause and effect relationships.

Ethnography: definition and development

It has been suggested that "The terminology of qualitative research is often confused" (Mackenzie 1994) and the comment is justified: in British nursing research the terms "qualitative", "grounded theory", "phenomenology" and others are more frequently used than they are defined. This makes the task of those who wish to assess the work of researchers more difficult than it need be:

> "The lack of clarity about terminology and the use of multiple approaches also pervade British studies and characterise the developing stages of qualitative research. Thus the methodology is obscure, and analysis of research reports using ethnography is difficult for those who wish to assess the potential of ethnographic research."
> (Mackenzie 1994).

"Ethnography" is used in this study in the sense described by Atkinson and Hammersley (1994:248):

> "In practical terms ethnography usually refers to forms of social research having a substantial number of the following features:
>
> - a strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them
> - a tendency to work primarily with "unstructured" data, that is, data that have not been coded at the point of data collection in terms of a closed set of analytic categories
> - investigation of a small number of cases, perhaps just one case, in detail
> - analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most"

Atkinson and Hammersley's description draws attention to the in-depth nature of ethnographic study, which is concerned with detailed analysis of the complexity of social relations and with the development of an analysis through this examination rather than the testing of pre-determined hypotheses in the study. Ethnography has its basis in a "naturalistic" perspective, outlined by Lofland and Lofland (1984:3):

> "Among the diversity of labels we could use, *qualitative social research* is probably the most general, encompassing and widely accepted ... Personally, however, we have a fondness for the term *naturalism*, or *naturalistic research* ... it suggests an appropriate linkage to *naturalist*, as that word is used in field biology. From the realms of philosophical discourse, it has acquired the connotation of minimising the presuppositions with which one approaches the empirical world - a laudable resonance indeed."

This stress on naturalism has been widely questioned in recent years and it is now qualified by concern to account for the influence of the researcher on the social world that is researched. Unlike the field biologist, the social researcher is a participating member of the world which is researched and so the relationship of researcher and topic is not as distant as Lofland and Lofland's comparison implied. It is for this reason that ethnographers now stress the value of reflexivity, which requires the researcher to explain his or her relationship with those involved in the study so that the reader can make an assessment of the effect of the researcher on the phenomena studied. This concern with reflexivity and the "post-modern" sensibility is illustrated by a number of the contributions to a handbook on qualitative research (Denzin and Lincoln, 1994).

Quantitative and qualitative methods in nursing research

There is a history of ethnographic studies in nursing, including examinations of the socialisation of student nurses (Melia, 1981) of relationships between health visitors and their clients (Chalmers and Luker, 1991) and the experiences of the families of children with eczema (Elliott, 1994). Its influence can also be detected in studies of the effects of health policy, for example Strong and Robinson's (1990) study of the effects of changes in the management structure of the NHS. There has also been extensive debate in nursing about the relative merits of quantitative and qualitative research. The tendency of authors to argue from the assumption that these are competing methods has led to a sterile debate about which is the better approach. It is more productive to regard quantitative and qualitative methods as complementary. The questions that are asked in a study, rather than the commitment of the researcher to a particular philosophical position, should determine the methods employed to answer them. The study of parental participation in the care of hospitalised children could be undertaken using quantitative or qualitative methods or a combination of both. The complexity of the social relations on a children's ward, with mothers and fathers sharing the care of their children with nurses was an important influence on the choice of method. It was apparent early in the study that it would be more productive to examine the experiences of a few families in some detail and to attempt to understand the complexities of their experiences than to attempt to categorise the data in advance and use quantitative methods. However, it is important to consider the account of parents' experiences within the context of the wider social structure within which the study was conducted. Class, race, gender, the organisation and financing of the National Health Service are among the structural conditions which may have affected the experience of the families in the study. Contextual notes are included in order to assist the reader to assess the influence of some of the structural factors on the experiences of the group considered in the study.

The preliminary study

A preliminary study was undertaken in the children's ward of a district general hospital. The purposes of the preliminary study were to assess the relevance of the research questions, to assess the feasibility of the main study methods and for the author to develop the skills required to observe, interview and analyse qualitative data. The preliminary study was a miniature version of the main study in which access was negotiated and data were collected and analysed as they were in the subsequent main study. During a period of two weeks medical and nursing records were reviewed and I attended ward handover meetings as an observer, making notes during and after the meetings. Tape recorded open-ended interviews were conducted with six nurses and the parents of children who had undergone surgery were recruited and tape recorded open-ended interviews were conducted with the mothers (and father in one case) of four children during the weeks after their discharge from hospital. Separate schedules of topics were developed to guide interviews with nurses and parents, partly in order to give an indication of the nature of the interview when seeking ethical approval and access and partly to provide an aide-mémoire to which I could refer during interviews. These schedules were developed from topics which seemed intuitively important or likely to encourage participants to discuss their experiences and from topics discussed in the literature review. The schedules were revised regularly during subsequent data collection and analysis to reflect topics that had emerged in interviews and queries or puzzles that emerged during analysis. As a result of this process of review the schedules were frequently amended in pencil and then in print and a selection of interview schedules is included in appendix 5 in order to indicate changes that occurred in the schedules from the preliminary and through the main study. As can be seen from the schedules included in appendix 5, the schedules were topic lists rather than questionnaires. I began interviews by asking parents to tell me their own story of their child's illness and reviewed the topic list as the conversation developed, raising any topics which had not been mentioned spontaneously. Unlike parents, nurses did not have a discrete story to tell which could form the basis of the interview which meant that the interviews with nurses in the preliminary study were more structured because I tended to ask questions rather than generate a conversation. During the main study I asked nurses to tell me about events on the ward that I knew about from participant observation, which resulted in more relaxed conversations. All interviews were transcribed and analysed along with the field notes made during the two weeks of observation of the ward.

The preliminary study confirmed that the topics in the interview schedules were of importance to participants and that it was possible to collect and analyse data by the selected methods. The preliminary study also indicated which methods of data collection were most useful, for example the handover meeting was a much richer source of data than the nursing records, where the most notable feature was often what was not written rather than what was. The preliminary study was time consuming and involved a considerable amount of work but this was justified by the confidence that I gained in the use of the methods of data collection and analysis and the evidence of the importance of the topics that I was studying to the parents and nurses who participated. Throughout the preliminary study participants were informed that this was a feasibility study in which I was "trying to find out if a larger study could be done", so that the investment of participants' time was made on the explicit understanding that this was preliminary work for a larger study.

Although the results of the preliminary study were encouraging, it was clear from the data that the district general hospital where the preliminary study was conducted treated children for predominantly minor conditions and that children were usually admitted for a day or two at the most. Therefore it was decided that the surgical ward of a children's hospital would be the most appropriate context for the main study. The sample that would be obtained from a children's medical ward would be strongly influenced by seasonal factors, for instance in the winter months the majority of admissions would be infants with bronchiolitis. The pattern of admissions to children's medical wards tends to be for children with minor conditions to spend very short times in hospital and for the longer admissions to be composed of children with chronic conditions that result in frequent hospitalisation. A children's surgical ward would provide a more balanced sample, including parents experiencing the only admission of their child to hospital and the parents of children who needed a number of operations. In addition, the longer admission of children that resulted from their need to recover from surgery would make it easier for me to make contact with parents while conducting a part-time study than would be the case with a medical ward. The literature has concentrated more on children's medical wards than on surgical wards and so there appeared to be more opportunity to gain new knowledge from studying the families of children admitted to a surgical ward.

Access

A consultant surgeon in a children's hospital was approached in order to arrange access for the main study. The surgeon selected had a reputation for a sympathetic approach to the needs of families and for good working relationships with nurses in the hospital. The study aims were explained to the surgeon who agreed that parents could be approached without setting any conditions on the study. Approval was also obtained from senior nurses and from the local NHS Ethical Committee. The informal negotiation of access is described in the account of the various methods used in the study.

Main study design

The study was designed with broad questions in mind in order to allow the study to be developed with sensitivity to the context and sufficient flexibility for the exploration of emergent themes.

A variety of methods was incorporated into the study design including documentary evidence, participant observation and interviews with both hospital staff and parents. The criteria used in sampling and the different methods used in the study are now discussed in turn.

Sampling

Children were selected for inclusion in the study on the basis of the following criteria:

1. The child had undergone surgery or examination under anaesthetic. This criterion was designed to ensure that all the parents had the common experience of their child being anaesthetised. The criterion excluded children who came to the ward for observation or routine investigations.

2. The admission had been for more than 24 hours. This criterion was designed to exclude very short admissions to hospital.

3. The parents spoke sufficient English to enable an interview to be conducted. Due to the limited resources available it was not possible to employ interpreters and so only English speaking families could be included in the study. There was one family whose English was judged insufficient and so were not asked to participate in an interview.

4. The child was not terminally ill. This criterion was included because the families of dying children have specific needs and their inclusion was neither appropriate to the study nor ethically justifiable.

5. The child was under the care of the consultant through whom access had been negotiated. Although it might have been possible to approach other surgeons, the relationship with one surgeon made negotiation of access and the development of a trusting relationship with the surgeon easier.

6. The child was not a teenager. This criterion was included in order to limit the study to children who were not independent of their parents. In fact one thirteen year old was included in the sample because he had a severe learning difficulty and chronological age was not a logical reason for excluding him as he was heavily dependent on his parents.

It was an intention to include a mix of children admitted for emergency and elective treatment and with chronic and acute problems. The sample that met the inclusion criteria during the study and whose parents I was able to approach included such a mix and so no special measures were necessary to selectively sample by these additional criteria.

Once a child had been selected, the parent or parents were approached, the purpose of the study was explained to them and they were invited to participate. An explanatory letter which explained the study was given to them and it was made clear that participation was entirely voluntary. A copy of this letter is included in appendix 1. If the parent agreed to participate I telephoned them in the weeks following their child's discharge from hospital and arranged a mutually convenient time for the interview.

Response

A positive response was given by the majority of parents. There were three stages at which consent could be refused or withdrawn. On two occasions the parent refused at the time of my first approach. Four parents agreed at this stage but then refused when I telephoned to make an appointment. A further three parents agreed in hospital and made an appointment with me when I telephoned but did not answer the door when I arrived at the appointed time.

Parents who refused to participate were not asked for reasons and since they were not interviewed no biographical data concerning them was available. It was interesting that only a small proportion of parents refused whilst in hospital. This might suggest that those who did not wish to participate felt so dis-empowered and passive that they did not feel able to refuse whilst in hospital. One mother who did refuse whilst she was in hospital spontaneously said "Oh I wouldn't want to live through this again", which suggested that she found the experience too stressful to agree to discuss in the future. However it would probably be a mistake to conclude that the parents who refused had suffered an especially harrowing time: other parents who accepted commented on how "traumatic" they had found the experience. I was always conscious that I was a man asking women for access into their homes. It would be quite understandable for women to be cautious about agreeing to be telephoned by a man and to invite him to visit them in their homes. Some women would check with their partners before agreeing and it is possible that some mothers withdrew their permission when I telephoned because of the reluctance of their partners. Two of the mothers who refused when I rang explained that this was due to their other commitments at the time.

Representativeness

The importance of context to the analysis of qualitative data means that sampling is of times and places as well as of people. For example, Darbyshire (1992) interviewed parents in hospital during their child's hospitalisation in order to "retain a sense of context". The choice of post-discharge interviewing of parents was more expensive in time and travel costs and gave parents more opportunities to decide to withdraw from the study. However, the timing of the interviews provided opportunities for parents to describe the whole of the hospitalisation of their children and to reflect on their experiences, which were sufficiently distant to reduce the immediate effect of upsetting experiences. In addition the choice of the venue of the participant's home was designed to take advantage of the confidence that comes from being on one's own territory and to reduce the extent to which the interview was associated with the particular hospital and staff that had cared for the child. The choice of time and place was made in order to reduce the reactivity that could result from the closeness of data collection to the hospitalisation.

Documentary evidence

A variety of documents were reviewed in the hope that they would assist in the development of an understanding of the context of the experiences of parents and the ward staff. It was hoped that this understanding of the context would be valuable when parents and ward staff were interviewed. The medical and nursing notes of children were reviewed in order to understand the particular context of each child's hospitalisation. Medical notes explained the reason for a child's admission and details of the child's medical history that provided some background and indicated whether the child met the inclusion criteria. Nursing notes provided limited additional information about the child and family's history and gave some information about the assessment and implementation of care. It soon became clear that the nursing notes were written after the hand-over and that most of the communication between nurses was oral rather than written. The hand-over report invariably proved to be a much richer source than the nursing records. Further documents available concerned the ward and hospital as the context of the parents' experiences. Off duty rotas were examined to provide evidence of staffing levels. Documents displayed around the ward, such as posters and memos were examined and observational notes made. In addition any other documents that were available were reviewed, for example a staff newsletter circulated by the management of the hospital.

Participant observation

Participant observation is often considered as the method of choice in ethnography. An element of participant observation was included in the design of this study because of the benefit that could be gained from close involvement in the ward. The value of participant observation was illustrated by comparison of the usefulness of reviewing nursing records and observing the hand-over between shifts. I attended the hand-over from the morning to the afternoon staff on Sundays from early September 1992 to late April 1993. Sundays were chosen because they were convenient to me and because this proved to be the best time of the week to contact parents staying with their children. There were no routine operations on Sundays and so parents were not waiting for their children to return from theatre. Routine investigations were usually conducted during weekdays and so parents were less likely to be away from the ward accompanying their children on visits to departments around the hospital. Sundays were not typical days because there was less activity on the ward but this was useful because it meant that the nurses were more relaxed and discursive during the handover and were more likely to be free to participate in interviews. I also attended other lunch-time handovers when this proved possible, usually on one week-day each week. I went to the ward before the hand-over and stayed for varying lengths of time afterwards in order to get a sense of what was happening on the ward. I visited the ward in the early evening on a couple of occasions but was surprised to find that the parents as well as the children had settled for the night by 8 p.m. and so abandoned attempts to approach parents at this time of day.

During the handovers the nurses listened to an account of each patient on the ward from the previous shift of nurses and discussed the progress of children, plans for treatment and problems or potential problems that had been identified. Most of the staff spent the entire report listening and taking notes and this was how I behaved during the handover. My role was therefore closest to that of "observer-as-participant" (Gold, 1958): I was clearly identified as an observer, wearing a badge marked "Peter Callery, Nurse Researcher" but I participated to the extent that I listened and took notes along with the nurses and shared in the mood of the meetings, which was at times serious, purposeful, sombre, frivolous, relaxed and rushed. I was not a "participant as observer" because I was not working and dressed as a nurse. However, neither was I a non-participant observer, because my presence in the handover was acknowledged and I participated by sharing in the responses of nurses to comments made in the meetings.

In addition to the hand-overs between shifts I spent some time waiting on the ward for meetings. This included occasions when I waited with the ward staff for the start of the hand-over, when I waited for members of the ward staff to finish other tasks before interviews and when I waited for parents to return to the ward. These occasions provided me with opportunities to legitimately stand and stare at the everyday world of the ward and to engage in informal conversations with members of the ward staff and parents. In all I estimate that I spent approximately 125 hours on the ward throughout the study. There was thus a limited but important element of participant observation in the study.

I recorded notes of events that I had observed during periods of participant observation after I had left the ward and on some occasions I made notes in a quiet place while on the ward. In addition I made detailed notes during hand-overs. The notes generated from participant observation were stored with transcripts of interviews and analysed along with the interviews. The greatest value of participant observation proved to be the topics it generated for discussion in interviews. Because I had been in the hand-over report I could refer to events and discussions that I had observed and nurses discussed them further with me in an open and frank way which often surprised me.

Interviews

Although participant observation was important the principal source of data was twenty four interviews with parents of children discharged from the study ward and twelve interviews with members of the staff of the study ward. The interviews with the ward staff took place in the hospital in the most private available room where interruptions were least likely. These interviews were arranged with individual members of staff and were conducted between September 1992 and March 1993. The interviews with parents were conducted in their own homes in the weeks following the discharge of their child from hospital. Interviews were arranged with the member of the family most involved in the care of the child in hospital, usually the mother, although other members of the family were not excluded and so it was that participants included mothers, fathers and grandparents. The interviews took the form of a conversation with the participants. Two lists of topics, one for interviews with parents and one for interviews with nurses, were used to ensure that the conversations covered all the areas that seemed relevant at the outset of the study. However, the lists were not exclusive and participants were encouraged to talk about the topics that were important to them. As the study progressed the lists of topics was extended and revised as new topics were raised by parents and nurses in interviews and as a result of my observation of the life of the ward. A process of informal analysis started as the data was collected. Preliminary judgements were made about data during participant observation and interviewing. These tentative judgements influenced the course of data collection because the emerging ideas would provide the basis for further questions or topics of conversation. This process of early, tentative analysis continued between interviews and resulted in amendments to the topic lists. Examples of the topic lists are included in appendix 5.

In the interviews I attempted to present myself as a sympathetic stranger with experience in nursing. The presentation of self by an interviewer is crucially important to the success or otherwise of an interview (Fontana and Frey, 1994). There were occasions where it was useful to feign ignorance of a subject so that the participant explained in more detail what they meant and I did not assume that we shared an understanding without question. However, it would not have been possible both to present myself as ignorant in order to be given an exhaustive explanation and at the same time present myself as experienced and so enjoy the benefits of the trust that results from a perception of shared experience. The tension between these potentially contradictory presentations of self meant that I had to tread a delicate path in order to retain a credible persona. I used communication skills that I have developed through training and practising as a nurse to encourage participants to speak freely and fully about their experiences. For example I used the techniques of echoing and rephrasing in order to encourage participants to expand on their comments and was careful to ensure that my non-verbal behaviour presented myself as interested in the comments of participants in interviews, even if they appeared to me to be of little interest or relevance at the time.

Strengths of the conversational interview in health care evaluation

Methodological studies of the use of consumer satisfaction surveys in evaluations of health services have found that users can give differing answers depending on the specificity of the questions that they answer. Locker and Dunt (1978) noted that :

> "the majority of patients will state that they are very satisfied with their care when asked to give an overall assessment. The same patients, however, express different levels of satisfaction when asked about various aspects of their care"

It is therefore important to ensure that the comments of consumers are related to specific aspects of their experiences, since global evaluations tend to provide a superficial view in which criticisms are suppressed. In the study interviews parents would make generalised comments about the hospital and the staff which were complimentary and non-specific, for example this mother of a baby who underwent elective surgery:

> Mother: And although they were probably short of money, as all hospitals are, I never thought that corners were cut. Like I say, the staff may have been overworked but I always felt that, on the whole, that nothing was too much trouble.
> Int. 20:17

Such comments could be made alongside discussions of more specific matters during which parents were critical of the services. Generalised statements of satisfaction have a hint of gratitude in them for the services that were provided and do not sound like the words of confident consumers. However, it would be a complacent reader who accepted the comment of the mother that is quoted above as an endorsement of the service because her words were measured and qualified: "on the whole nothing was too much trouble" suggests that on some occasions some things were too much trouble and the statement is preceded by a comment about a shortage of resources, implying that the assessment of the hospital had to be considered in the context of an under-funded service. It would appear that parents, like other users of health care services are reluctant to make generalised condemnations of the service that they received but will make criticisms if given opportunities to discuss specific experiences. The mother's comments, then, indicate how she saw the NHS (as an under-funded service where deficiencies are to be expected) and how she saw her relationship with the service (as an observant but grateful recipient of the service rather than as an outspoken consumer).

Open ended interviews in which participants are given the freedom to raise and give precedence to the topics that seem of importance to themselves, are of particular value in health care evaluation. Although questionnaire surveys of patient satisfaction are widely used many have been criticised on conceptual and methodological grounds (Carr-Hill, 1992; Fitzpatrick, 1991). The critique of questionnaire surveys includes four key points: 1) the agenda is set by the designer of the questionnaires, 2) questionnaires are not sensitive instruments for dealing with complex and emotive matters, 3) sampling is often selective and 4) questionnaire completion is a passive and limited form of participation in evaluation (McIver, 1991). For these reasons there has been an increasing interest in the use of ethnographic methods in the evaluation of health care services (Rigge, 1994; College of Health, 1994). The conversational interview has the potential to allow participants to set the agenda of the discussion and to stress what is important to themselves. Conversational interviews also provide opportunities to explore complex issues in some depth and for the participant to give detailed explanations rather than the simplified responses that are usually required in questionnaires.

Ethical considerations

Organisational review of research proposals is a necessary but not always a sufficient condition to ensure that adequate consideration has been given to the ethics of a study. The study was subject to the usual requirements for committee review. Permission to approach parents was granted by the consultant responsible for the care of their children. The study proposal was reviewed and approved by the local NHS Research Ethics Committee. The nursing management of the study hospital gave approval for the nursing staff to be approached. Although this review at the organisational level was important further consideration had to be given to ethical dilemmas that could arise in the study.

The most important consideration in this study was that participation was based on informed consent. The study was explained to parents while they were in the hospital and they were given a letter that re-stated the points made in the verbal explanation. The letter was typed on University of Liverpool headed note-paper and so parents had an address they could write to and a telephone number that they could ring for further information if they so wished. A copy of the letter is included in appendix 1.

In addition to ensuring that consent was informed it was also important to ensure that consent was voluntary. The territory on which parents decided whether to participate assisted to ensure that their participation was voluntary. Parents were asked if I could telephone them once they were at home to make an appointment to interview them. This meant that the decision about whether to proceed with the interview was made by the parents in their own homes rather than in the hospital and that time had elapsed for them to reflect and decide whether or not they wished to participate. There are many ways in which consent can be coercive, for example the social context in which a person is asked for consent can influence their response. The methods used here ensured that parents were given ample opportunity to refuse or withdraw their consent to participating in the interviews. The refusal of some parents to participate illustrates the extent to which they felt able to refuse and suggests that parents did not feel obliged to participate in the study.

Nurses were also asked to participate in interviews and the principles of informed voluntary consent were adhered to in requests of nurses for interviews. However, participant observation presents more complex problems in ensuring informed and voluntary consent. There is a tension between the need to limit reactivity, the influence of the researcher on the world observed, and the ethical requirement to ensure informed and voluntary consent. The demand to limit reactivity can in extreme cases lead to concealment of the purposes of the researcher. I met with all the ward staff before starting the study in order to explain the purposes of the study and to enlist their agreement. However, because of the nature of the study the explanation given to the nurses at this stage was necessarily incomplete. I did not know myself at this time what all the topics of interest would be because the methods were designed to uncover the topics of importance to the participants. It was only possible to give a general account of the intentions and purposes of the study and to suggest how the nurses might be asked to co-operate in the study. Even this explanation was not available to all the participants at this stage. Other members of the ward staff were not available at this point, for example the students who were to be allocated to the ward during the study. It was therefore necessary to introduce myself to new members of the ward team and explain the purpose of the study as I met them.

The limits of the interview

It is important for the interviewer to be clear about the limits of the role of interviewer. While participants might value the opportunity to discuss experiences that were upsetting, it would be inappropriate for an interviewer to attempt to provide therapy. The purpose of the interview was made clear to parents throughout. If a concern had arisen about the health of a parent during an interview, I would have advised them of sources of professional help. There were occasions when parents were concerned about aspects of their children's health and treatment but I was able to establish on each of these occasions that the parents would be able to raise their concerns with the appropriate professionals within a safe time-span. On one occasion a parent asked me for advice on a complaint that she wished to make to a hospital (not the study hospital). I gave the advice that I would have given to a neighbour who might make a similar enquiry, that is simple factual advice about the appropriate address for the complaint. Care was thus taken to ensure that the role of interviewer was limited and the relationship with parents was not extended into areas that were not appropriate.

Reliability and validity of the methods of data collection

In this section aspects of reliability and validity relevant to the methods of data collection used in the study are discussed with reference to selected texts from the methodological literature.

Post-discharge interviews and retrospective recall

A consequence of the use of post-discharge interviews as the principal source of data is that the accounts of parents are retrospective. While interviews conducted in hospital risk the reactivity that results from the influence of the hospital context, it could be argued that post-discharge interviews are vulnerable to the vagaries of memory. The decision about when to interview is not straightforward but as Carr-Hill (1992) suggested it is an important decision:

> "The timing of surveys [of patient satisfaction] may also be of critical importance. The longer the gap between the use of services and the interview (or the questionnaire) the greater the chance of recall bias, of respondents overlooking matters that affected them during the episode of care, and of changes in their appreciation of services."

The problems of recall were limited in the study design by time-tabling the interviews with parents for the weeks following the discharge of their children. In Carr-Hill's comments it is notable that the factor which is most stressed is the length of time between the use of the service and the interview. Most of the interviews took place between three and five weeks after the discharge of the child from hospital, although two were conducted six weeks after discharge. The length of time between discharge and interview meant that the events of the hospitalisation were still fresh in the parents' minds: this had been a major event in their lives which made an impact on them. It is unlikely that the parents had forgotten much of the experience both because it was recent and because of its profound nature. The memory of a mundane contact with health services, for example treatment for an in-growing toe-nail, is likely to fade more quickly than that of an emotive contact, such as one's child having surgery under general anaesthesia.

One of the underlying concerns that led to the study was the extent to which parents could choose whether to be involved in their children's care and so the extent to which parents retained their autonomy. Retrospective interviewing was therefore particularly appropriate because autonomy has been defined in terms of second order desires (Dworkin, 1988). Dworkin suggested that autonomy should be conceived of:

> "as a second order capacity of persons to reflect critically upon their
> first-order preferences, desires, wishes and so forth and the capacity to
> accept or attempt to change these in the light of higher order
> preferences and values"
> (Dworkin, 1988:20).

The parents of hospitalised children might say while they were in hospital that they wished to participate in their child's care as a result of pressures to conform to social expectations which could lead them to want to participate even though they did not wish to do so. The use of retrospective interviews minimised the effect of social pressures in the hospital and gave parents the opportunity to reflect critically on their experiences. Post-discharge interviews were more likely to reflect the second order preferences of parents than either participant observation or interviews conducted during the hospitalisation.

The problem of assessing the validity of interview data

Although interviews are commonly used in qualitative research, the status and validity of interview data are the subject of debate. It has been suggested that:

> "within the qualitative perspective, data generated in the interview context present particularly difficult problems of interpretation" (West, 1990).

The debate about the interpretation of interview data arises because the data is generated through a social process that is organised for the purpose and consequently data is not sampled from a "naturally occurring" source. West argued that

> "People, it seems, are eminently capable of talking about an issue in different and apparently contradictory ways. This is not simply a consequence of the vagaries of memory, though that may play a part, but of the type and level of discourse they engage in at different times, in different contexts and for different purposes."

The solution offered by West is to consider accounts as either "public" or as "private". West suggested that "public" accounts are produced from interviews that take place at an early stage in the relationship between interviewer and interviewee. The presentation of direct questions to participants results in "public" accounts characterised by responses which deal with the "generalised other" and present a "managed appearance". "Private" accounts, by contrast, are presented in interviews conducted later in the relationship where the participants recount stories about their experiences and deal with meanings that are derived from the experiential world. The implication is that "private" accounts are more truthful than public accounts.

The interviews discussed in this study share features of both "public" and "private" accounts. Location of the discourse was one of the factors that West highlighted. The interviews with parents were conducted in the privacy of the parents' homes, in contrast to Darbyshire's (1992) study in which parents were interviewed in hospital. Parents recounted their own stories about their experiences and their accounts included discussion of specific experiences. These are features of West's "private" accounts. However, the fact that parents were interviewed on one occasion only and by a researcher who was also a nurse might suggest that the accounts also had "public" characteristics.

The distinction between "public" and "private" accounts is too rigid. A mother who was interviewed with her partner appeared to find it difficult to explain her experiences to him but talked about them in the interview as if she believed that she was understood:

> Mother: You [to husband] got a different picture altogether, but for me whilst I was there, it was one of the worst times of my life. All the worry and the emotions you go through whilst you were there, it was absolutely incredible.
> Int. 41, 2 Mar 93

Later, when her partner had left the room she said:

> Mother: As I say Jeff [husband] doesn't realise what it was like because he wasn't there 24 hours like I was, but I find the emotions that you go through whilst you were there, you go through so many emotions.
> Int. 41, 2 Mar 93

This mother's public account to an interviewer appeared to be more open and less inhibited than her private account to her partner, reversing the usual public/private distinction. The distinction is therefore of limited value: accounts by the same person may differ in different contexts but the distinction between private and public does not capture the richness of these differences. The concept of moral competence (Silverman, 1985) is more useful when interpreting interview data. The suggestion that participants may present themselves as morally competent in an interview is consistent with the idea of a "public" account which is socially acceptable and in which discourse that might be seen as deviant is suppressed. However, the presentation of moral competence is a more flexible concept, which can allow for the presentation of different forms of competence in different circumstances and does not rely on an either/or distinction between "public" and "private" accounts.

The validity of interview data rests to a large degree on the honesty with which participants speak about their experiences. The participant is not expected to give the disinterested account of an uninvolved observer but to talk frankly and honestly about their own perspective of an experience. This is necessarily partial and the partiality is important because it is the view that the participant had of an experience that is of interest.

The potential problem of participants' accounts being misleading is fundamentally a question of the extent to which the accounts can be trusted, of the credibility of the interviews. In order to ensure that good quality data are generated the principles of ensuring voluntary participation, establishing trust and respecting the participant's point of view are helpful. Participants who voluntarily consent to a study have less reason to lie, or simply to acquiesce passively in order to present socially acceptable answers, than those who have been coerced or duped into participation. This principle is a necessary but not a sufficient condition for interview data to be valid. It is also important that the participant trusts the interviewer. This is important because a fear of how comments might be used could inhibit participants if they doubted the assurances of confidentiality that were given to them. Trust is also important at the interpersonal level: if participants believe that they can openly discuss their feelings they are less likely to suppress or reconstruct them for an audience. The principle of respecting the participant's point of view is essential in order to establish trust with participants and it is also important to the subsequent treatment of the data.

Gaining the trust of participants

Where the interviewer is trusted the audience to which the participant speaks will be a trusted listener rather than a moral jury to which the participant is called to account. In order to establish trust in myself as the interviewer I sought to make myself less of an outsider and more of an insider in the world of the participants. There is a tension between the advantage of the trust that can be built through becoming an insider and the disadvantage of losing the critical distance that is necessary if one is to study the social world effectively. Context is important to the discussion of this tension and the next two sections discuss the tension in hospital and in the homes of mothers.

a) Parents

Because the interviews with parents were conducted in their own homes I was physically an insider as a guest in their house. This gave me opportunities to discuss features which I observed in the houses. For example, in early November I was surprised to see a fully decorated Christmas tree taking pride of place in the lounge. When I commented on this I was told that the child had been promised while in hospital that the tree would be put in place when he went home. The Christmas tree was interesting because it revealed the parents' uncertainty of the timetable of the admission, their use of rewards to persuade the child to comply with treatment and the power of the child to enforce a promise that might have looked unreasonable following discharge.

Clues were given by parents about how they viewed me and the purpose of the study. On some occasions when a parent answered the telephone they would explain that "somebody's here from the hospital" which could mean that they had chosen to adopt a short hand which avoided further explanation or could suggest a mis-understanding that I was employed by the hospital. The impression that most parents gave was that they saw me as a nurse but one not associated directly with the ward. For example one mother apologised to me for having concealed a flask of tea on the ward (in contravention of the rule that hot drinks were not allowed on the ward) but did so in a mildly ironic way so as to suggest that she did not really believe that I was associated with the rules of the hospital.

Parents seemed to want to talk about their experiences. In some cases where parents had found their experiences particularly difficult they appeared to regard the interview as a form of self help. For example the parents of a child who had been struck by a car had put their children to bed early and were tensely preparing to relive their experience when I arrived. Others were more relaxed and the interview fitted in with their evening's activities rather than the other way round. The parents of another child said that they had wanted me to come around sooner because they were so anxious to talk about their feelings. The participants were for the most part enthusiastic volunteers who wanted to talk about their experiences and needed little encouragement to start giving their accounts. Far from being influenced by the questions that I put, they often gave me few opportunities to influence the course of the conversation.

Although I shared the experience of being a parent, something which I did not volunteer but which parents would often ask, I was an outsider to the participants in an important respect. The parents who stayed in the hospital with their children were usually mothers. It was therefore inevitable that as a male investigator I was to some degree an outsider. This was of most significance when I felt constrained in the line of questioning that I could take. When I discussed the toilets and washing facilities for mothers on the ward with a woman her reaction was to question how mothers who were menstruating coped with life on the ward. It might be that a woman could have broached such a personal subject in the interviews but I found that I could not because I feared the reaction of the women to a man asking about this subject.

b) Nurses

The comments of nurses indicated how they understood my presence on the ward during the study. Early in the study, when I started attending lunch-time handover reports a staff nurse joked "Have you come to hear the gospel according to Mark again?", which implied that I was an unusual member of the group who met in the sister's office for this meeting. Nobody else would be asked this question because all the other members of the group were attending the meeting either to report on their morning's or to prepare for their afternoon's work and so the strangeness of my position was acknowledged. In spite of the introductions of me by the senior sister some staff were not sure who I was, because they were not working on the shift when the study started and on one occasion a staff nurse challenged me to explain what I was doing. I used the ward handover reports as an opportunity to discover the details that I needed to know before approaching families and as an opportunity to discover interesting cases that I could discuss with the nurses in our interviews. However, the most important function of my attendance was to become as much of an accepted insider as possible. After some weeks another comment by a staff nurse suggested to me that I was accepted as almost a member of the nursing team. After the report she said "Would you like some children to look after Peter?" in a jocular manner. The comment confirmed my status as a nurse and also as a nurse who was not on the ward to look after children. I was therefore an insider but not a member of the team, as one of the nurses said "You're almost one of the team"- almost but not quite.

It seemed prudent to adopt a cautious approach and to give the staff plenty of time to get used to me. The caution I exercised is illustrated by the fact that I only started to write notes after approximately 3 months of the study. Sunday lunch-time proved to be the time that was most convenient for attending the handover report, both because this was a time that I could be sure of being free to attend and because this was a time when the families were usually on the ward. I also attended on weekdays when this proved possible but my attendance on Sundays seemed to confirm my status as a nurse. During the week other workers would be present on the ward but the only workers there at the weekend were nurses and medical staff on call.

My presence in the handover confirmed that I was a nurse and could have access to the information that was available to other nurses. For example, during one of the early reports that I sat in a staff nurse paused during her account of a patient and asked the sister how much she could say. The sister reassured her that she could give the full account in front of me.

I was recognised by the hospital staff as a children's nurse and this gave me access to informants and information that might otherwise have been restricted. Because I was known to be experienced in the care of children, the staff would use technical terms in their conversations and refer to aspects of children's nursing, without having to explain each term or reference to me. The familiarity of language both meant that conversations were less self-conscious than if it had been necessary for the staff to explain themselves and also confirmed me as a member of their professional community. I was accepted by the nurses as a colleague who could be trusted with sensitive information. One of the senior nurses said that people trusted me because they knew that I was a Registered Sick Children's Nurse. Presumably the basis of this trust was that the nurses felt that I would understand some of their problems and would therefore be sympathetic to their aims and difficulties.

The advantage of being an insider in the hospital was that the hospital staff would be open with me about information which might be regarded as sensitive. However, there are disadvantages as well as advantages in being an insider. The group of sociologists based in Swansea who studied children's wards saw the "unintended distress" caused by the working practices of the staff (Stacey, 1988:204). Presumably it took outsiders to see what was happening, otherwise the distress would not have been unintended. Similarly practitioner research has been criticised on the grounds that the insider's understanding of the social world is determined by their place in it. Hammersley (1992) suggested that practitioner ethnography makes claims for insiders which are not justifiable.

The insider perspective can provide an insight into the social world which is not available to an outsider. However, Hammersley argued that being an insider creates methodological difficulties. Hammersley suggested that while practitioners may claim to understand the context which they study, their particular roles give access to some information but not to others. An implicit and unseen form of processing serves the concerns of the practitioner researcher. This is an important point: there is an obverse side to the benefits obtained by being an insider and this is that the insider has a narrow perspective. Whilst being a partial insider I also found it necessary to maintain a critical distance from the practitioners that I observed. I felt sympathy and concern for the difficulties with which they had to work, for example the pressures on their working time. It was therefore important that I retained elements of the "outsider", for example not being involved in the daily work of the ward and not becoming a full member of the ward team: remaining a familiar and accepted person with a distinct and different role. The requirement was to obtain the benefits of understanding the work of the ward whilst avoiding the danger of uncritically accepting the very "taken for granted" which I had come to study.

Analysis of data

Immersion in the data

Interviews were tape recorded and the majority of the tapes were transcribed by a professional secretary with experience of dealing with confidential material and of discrete handling of sensitive information. However it remained possible to ensure close attention to the data whilst securing the benefit of cost effective transcription. Following transcription I checked every interview transcript against its tape recording, corrected mistakes and added notes about non-verbal behaviour. The transcription was duplicated after the completion of corrections and read again, when one copy was marked with open codes. Open codes were broad categories that grouped data very loosely. An example of an open code was "uncertainty", which included a large number of comments that suggested a variety of forms of uncertainty. During a further reading, which was deliberately delayed until some time later, the codes were reviewed, checked for their appropriateness and amended if necessary before a second copy of the interview was cut and pasted onto cards and filed under the code heading. A further copy of the interview was left un-marked in case the need arose to read the transcription entirely afresh at a future stage. By this means each interview was closely listened to at least once and read attentively at least three times. The effect was for the data to become as familiar as when I had transcribed the tapes myself.

Rejection of computer assisted analysis

The coding of data was done by the traditional methods of photocopying, cutting and pasting pieces of paper. There are software programs which enable these procedures to be conducted electronically, including The Ethnograph, NUD*IST, HyperResearch and Atlas. When I started the analysis I was wary of attempting to learn both the techniques of qualitative analysis and of the use of software at the same time. In addition I was unsure of the consequences of using software for the development of the analysis: would the software program structure the analysis in a way that seemed inappropriate? The safe option seemed to be to use pieces of paper. Some correspondents on the Qualsoft list (an Internet discussion group about the use of software programs for the analysis of qualitative data) have raised similar concerns and suggested that novices should learn the methods by traditional means before attempting to use computer programs. However, the opportunities for increasing the efficiency that computer programs offer are likely to make the methods of cutting and pasting used in this study seem quaint within a few years.

Initial coding

The initial coding process followed the principles described in social science methods texts (Lofland and Lofland, 1984; Strauss, 1987). The principles of open coding outlined by Corbin and Strauss (1990) were also drawn on at this stage of the analysis. The data were fractured and tentatively placed within one or more open codes. This phase was predominantly descriptive and was characterised by a cautious attitude where firm conclusions were avoided. However, initial attempts were made to identify patterns in the data by writing memos that drew together items of data into provisional relationships and questions were posed that guided the processes of data collection and analysis. A sceptical attitude was maintained and in subsequent data collection and analysis there was an active attempt to search for inconsistency with the pattern as well as for confirmation.

Transcription, checking of transcriptions, initial coding, cutting, pasting and filing proceeded concurrently with data collection so that at any stage after the initial interviews each of these activities was progressing. Concurrent data collection and analysis is recommended in qualitative analysis because each process can enhance the other. In this study the benefits of concurrent data collection and analysis were obvious from an early stage and included assurance of the quality of interviews as well as the development of new lines of enquiry.

The analysis of early interviews provided opportunities to improve the quality of interviewing technique because effective and ineffective techniques could be identified and the lessons learnt incorporated in future interviews. Concurrent analysis also made it possible to include new lines of enquiry that emerged from earlier interviews and to amend or in some cases to discard emergent explanations which were not supported by the data. Because the decision to discard was taken cautiously but to explore new lines of enquiry readily, the interviews tended to become longer as the study proceeded.

Development of analysis

As the analysis proceeded some of the early codes were re-cast or discarded. Items of data were grouped into smaller, more specific codes, although the filed cards were left in their open coded groups in order to avoid the danger of closing off emerging options for analysis. The grouping of fractured data became more theoretical and less descriptive and was conducted in a less hesitant manner. However, a sceptical attitude prevailed and data were not categorised unless there were convincing grounds for doing so and the context would not undermine the categorisation. At this stage a benefit of the initial process of immersion in the data became evident. Whilst the data were now fractured into small items that had been cut and pasted, the sense of context was not lost and it was possible to recall the context of the child and family when considering individual items of data.

Once all the data had been collected the process of analysis moved to a more theoretical level. The various stages of analysis continued concurrently but the writing of memos became more ambitious in two ways. Firstly, the scope of the writing was widened in order to consider coded data at a broader more theoretical level. Secondly, the patterns that had emerged in the data were actively compared with the literature and searches of the theoretical literature were conducted and this led to the inclusion of theoretical material in the analysis. At this stage attempts were made to explain the data in terms of existing theory and to identify ways in which the emergent patterns in the data departed from existing theory.

Example of the development of analysis: findings concerned with maternal and professional knowledge

The emergence of the analysis of findings concerned with maternal and professional knowledge illustrates the process of analysis. During the interviews some mothers spontaneously mentioned problems that they had experienced in their dealings with professionals, for example in interview 29 the mother described conflicts which she had experienced with doctors when she felt that her child was in heart failure. In interview 31 the mother talked about the difficulty that she had experienced in convincing the professionals that her child had a problem. The experiences of some mothers seemed to suggest that parents might be able to identify problems with their child that the professionals could not. In subsequent interviews if parents did not spontaneously discuss their own knowledge and the response of professionals I steered the conversation around to the topic. A category of "Maternal/technical knowledge" contained the data that seemed to refer to the ways in which parents felt that they knew that their child was ill and the conflicts that they experienced with professionals.

After the completion of data collection the group of data which was contained within this open code was reviewed and became the subject of draft papers which sought to explain the experiences described by the mothers. These papers led to searches of the literature concerned with the professional consultation and lay understanding of illness. The data was then re-considered in the light of this literature. Some patterns within the data could then be explained, for example the mother's comparison of the current signs with the normal for the child was consistent with the patterns described by Cunningham-Burley (1990) in her study of mother's identification of mundane illness in children. An explanation of the data was then developed which integrated this literature and also enabled the variety of experiences described by parents to be explained.

The process which has been described above ensured that the participants raised the subjects that seemed important to them. The starting point of the analysis was therefore the experiences of the participants. The analysis started with data that needed explanation and so the explanation was grounded in the data. The search for explanation led to review of areas of literature that now appeared relevant and the comparison of patterns in the data with the literature. Consistency of the literature with the data was tested and areas of inconsistency led to further searches for an explanation.

Validity of data analysis

One of the most problematic questions in qualitative research is how to assess the validity of the analysis. There are established procedures for testing the internal and external validity of quantitative methods and these place a strong emphasis on the measurement of reliability. The concept of reliability does not sit comfortably with ethnography. At the level of common sense it is inappropriate to demand that an interview or observation in the social world could be replicated by other researchers so that the result is predictable. However, it is not satisfactory to criticise positivist approaches without offering an alternative approach to the assessment of validity. In this section different approaches to the assessment of validity in qualitative research are considered.

Rejection of inter-rater reliability

One approach to the problem of validity arises from the quantitative concern with reliability and replicability. The procedure is to test the inter-rater reliability by engaging a second analyst to repeat the analysis and to check for agreement between the two. The approach rests on the assumption that there is one correct analysis of the data and that with sufficient competence and diligence any analyst would produce the same result. Where complex data are analysed it is unlikely that there will only be one correct analysis because any single item of data is reviewed within the context of an overall picture of the data and the comparisons that are made by any analyst might well differ. In order to ensure agreement it would be necessary to reduce the level of inference drawn and to require manifest evidence for the coding of a piece of data (Holsti, 1969) with the result that only the most superficial analysis could be agreed on. The result would be a naive reading of the data which could itself be misleading. The procedure of inter-rater reliability was therefore rejected as inappropriate to this study.

Rejection of respondent validation

An alternative way of checking the analysis is to return to the field and ask the participants to review and comment on the account in order to seek respondent validation (Reason and Rowan, 1981). Whilst this appears attractive at first sight there are both technical and more importantly methodological problems. The technical problems concern keeping contact with what may be a moving population. A methodological problem is that while the participants know their own view of the world they do not have the whole set of data to assess (Sandelowski, 1993). There is also the fundamental assumption that respondents are able to judge whether an analysis is correct. If this were the case there would be no need for the research in the first place, because the participants would simply need to record the truth that they already know. The whole point of the analysis is that the analyst seeks to understand the world in a new way: if this depends on the analysis being acceptable to the participants then it is more likely to be a banal repetition of assumptions that participants already hold or even to be an account edited to present a public face of moral competence.

Avoiding over-interpretation

The problems involved in respondent validation are paralleled in the interpretation of literary texts. In both cases the right to interpret the text passes from the author (or interview participant) to a wider readership. An important debate in literary criticism is the relative weight that should be given to the intentions of the author and the interpretation made by the reader and there are extreme views on both sides, on the one hand stressing the purpose of the author and on the other suggesting that once produced the author's text belongs to its readers. The analysis of these problems by Eco (1992a and b) contains some amusing accounts of how his own novels have been re-interpreted by readers in ways that he had not intended and of also of how he realised that unintended meanings had been communicated through the text. Similarly the analysis of ethnographic interviews is not controlled by the interviewees. The purpose of interviewing is to enable the participant to talk freely and to say what they want to say and perhaps also to say things that they are not consciously aware that they are saying. Interviews are most successful when the interviewee is un-self-conscious and gives an account which has not been edited for the benefit of an audience. The conscious intentions of the interviewee are therefore not the most important consideration in the analysis of an interview. The process of analysis is more than reporting what was said by the interviewee and the very fact that analysis is undertaken implicitly states that the interviewee does not control the interpretation of their "text". The problem in literary criticism is similar:

> "Someone could say that a text, once it is separated from its utterrer (as well as from the utterer's intention) and from the concrete circumstances of its utterance (and by consequence from its intended referent) floats (so to speak) in the vacuum of a potentially infinite range of possible interpretations."
> (Eco, 1992a: 41).

But if any interpretation is possible then none is of much value. How can this problem of the worth of interpretation be resolved? Eco suggested criteria for dealing with this problem:

> "...there are certain 'economical' criteria on the grounds of which certain hypotheses will be more interesting than others. To validate his or her hypothesis, the addressee probably ought to make certain

> previous hypotheses about the possible sender and the possible historical period in which the text was produced. This has nothing to do with research about the intentions of the sender, but it has certainly to do with research about the cultural framework of the original message."
> (Eco, 1992a:.42).

Thus the analyst is not concerned with what the intentions of the interviewee when comments were made during the interview but with understanding the text in its context. This is easier if the analyst was also the interviewer and thus not only present at but also closely involved in the production of the text.

Eco suggested criteria by which interpretations can be judged:

> "...evidence is considered as a sign of something else only on three conditions: that it cannot be explained more economically; that it points to a single cause (or a limited class of possible causes) and not to an indeterminate number of dissimilar causes; and that it fits in with the other evidence."
> (Eco, 1992b:48-9).

For the reader, Eco suggested that:

> "...we can accept a sort of Popperian principle according to which if there are no rules that help to ascertain which interpretations are the 'best' ones, there is at least a rule for ascertaining which interpretations are 'bad'."
> (Eco 1992b:52).

Eco's comments about textual analysis provide some pointers for the reader of a qualitative text, suggesting that the reader applies certain tests to the interpretation and evidence provided to support it.

Deviant cases

The crucial question for the reader of a piece of qualitative analysis is the fate of the deviant case during the development of an explanation by the analyst. The handling of cases that do not fit the developing explanation is central because it can either undermine or enhance the credibility of the study. The worst suspicion that a reader can have is that the analyst has suppressed the cases which did not support the explanation. In such a case the work of the analyst would be dishonest as well as misleading. Unfortunately it is not unknown for scientists whether using quantitative or qualitative methods to be dishonest and there is little protection against unscrupulous researchers.

Deviant cases are dealt with in quantitative research by identification of the degree of deviance to be found in a given sample, for example by measurement of the standard deviation. Deviant cases may alternatively be seen as an opportunity to enrich the explanation rather than as a threat to the integrity of the explanation, for example Strong (1979) described how considering the deviant case of private health care in the USA helped to sharpen the focus of his explanation of consultations in the UK. By re-formulating the explanation in order to accommodate deviant cases the analyst produces a more thorough explanation. The principle of falsification that Popper suggested underpins hard science is therefore approached slightly differently in qualitative research. In both approaches the deviant case that does not fit the theoretical explanation is sought but in qualitative research the explanation is expanded and adapted to accommodate deviant cases. In hard science deviance is measured and either rejected as statistically insignificant or accepted as sufficiently significant to enable rejection of the hypothesis. The most important test of a qualitative analysis is evidence of the discovery of deviant cases and their inclusion in the explanation that is offered. The level of complexity of the explanation gives some indication of the degree to which it is based on a rich data-set that includes diverse cases.

Plausibility and credibility

The criteria that are recommended by Hammersley (1991) are that the explanation offered should be plausible and credible. Thus the explanations should "ring true" and should seem to the reader to make sense as an explanation of the data that is presented. Hammersley laid stress on the community of academic readers and their assessment of the plausibility and credibility of the explanation offered. Hammersley has been criticised for not placing more stress on the "relevance" and "importance" of the explanation (Altheide and Johnson, 1994) but this criticism risks implying that only "politically correct" explanations are valid.

Criteria for reading ethnography

The task of the reader of an ethnography is to read the text critically in order to assess the evidence provided for the interpretations made, to judge whether context has been taken into account, to consider the economy of the interpretations and the evidence that deviant cases have been allowed for.

Summary

In this chapter the processes of data collection and analysis used in the study have been outlined. Potential sources of reactivity have been identified and the efforts that were made to reduce threats to validity have been explained.

CHAPTER 3: THE CONTEXT OF THE STUDY

Introduction

In this chapter the context of the study is described. Firstly the work, staffing and design of the study ward are described. Details are also given about the characteristics of the sample of children and their parents. Finally the role of parents in the hospital is discussed.

The study ward

The study was conducted in a surgical ward of a children's hospital in the North of England. Like other paediatric surgical wards in specialist children's hospitals the ward accepted referrals from paediatricians in the wider area of the regional health authority's responsibility as well as from local General Practitioners and Accident and Emergency departments.

I was given access to parents and the medical records of children admitted to the study ward by a consultant paediatric surgeon who readily agreed to co-operate with the study. The consultant was the most recently appointed of those who worked on the ward and had a reputation for progressive attitudes towards both nurses and parents. This reputation suggested that the consultant's practice was likely to be sympathetic to parents and to the purpose of the study and it was for this reason that I approached this particular consultant to ask for access.

In early meetings to discuss the study the information given to me was that the pattern of referrals to the consultant was similar to that of the other surgeons working on the ward. The observations that I made during ward hand-overs and of the activity on the ward meant that I was aware of the conditions and treatments of all the children present on the ward and not only those admitted under the care of the consultant who had granted access. My impression from these observations was that the study consultant's caseload was not noticeably different to that of the other surgeons. The majority of the work of the ward was concerned with elective surgery on the renal tract, including repairs of hypospadias, re-implantation of ureters and other treatments for congenital malformations. In addition children were admitted for a variety of other elective surgical investigations and procedures, mainly concerned with abdominal problems. Emergency admissions for conditions that potentially might require surgery, such as abdominal pain or head injury formed the remainder of the work of the ward. Many children were admitted and discharged within a couple of days and had relatively minor surgery or simple investigations. There were also children with problems that were both severe and chronic. There was a group of children who attended the ward regularly for surgery and investigations and were well known to the ward staff.

The nurses

The study ward was predominantly staffed by Registered Sick Children's Nurses (RSCN) who were supplemented by two part-time enrolled nurses, one full-time and two part-time support workers, a nursery nurse and a part-time ward clerk. The staffing levels meant that there were usually two Registered Sick Children's Nurses on each morning and afternoon shift. On some occasions there would only be one RSCN. These qualified staff would usually have one member of the non-registered staff to assist them throughout the shift. It can be seen from the sample off duty rota (appendix 2) that staff rotated between day and night duty and that student nurses were not included on the duty rota. The ward provided placements for students from a variety of courses, from Common Foundation Programme students for whom this might be one of their first ward experiences to qualified nurses who were working for an additional qualification.

The full-time RSCNs appeared to be predominantly in the age range 25 to 35. During the study two RSCNs left for other posts. None of these nurses had children of their own, although there were part-time nurses who were also mothers. All the nursing staff were female.

A number of the nurses were studying part-time for qualifications relating to their work. Three at least were studying for diplomas or degrees in nursing and one was attending a course in counselling.

The study ward nurses were a relatively young and enthusiastic group of staff. There was a degree of turnover of staff and it was my impression from informal conversations with them that most had not been in their posts for more than a couple of years.

Ward design

The study ward had sixteen beds, although it had been built to house a further six beds these were not funded and a six bedded bay was used for storage. A diagram of the lay-out of the ward in included on page 117. It can be seen from the diagram that the beds were arranged in two six bedded bays and four side-rooms. Two of the side-rooms each had a bathroom and toilet attached, the remainder of the ward was serviced by a communal children's bathroom. Parents could either sleep in a collapsible bed next to their child or stay in the parents' unit, which was accommodation situated away from the ward and was provided for parents of children admitted to any of the wards in the hospital.

Characteristics of the sample

The inclusion criteria meant that the sample was taken from the children who were admitted to the ward for the longest stays and who had the most severe problems. The majority of children in the study were admitted for elective surgery to their renal tract. *Table 1* shows the distribution of types of surgery amongst the children in the sample. A more detailed table which shows the full range of conditions suffered by children in the sample is provided in appendix 3.

Table 1: **Types of surgery undergone by children in the study**

	Abdominal	Renal tract	Other	Total
Emergency	4	1	2	7
Elective	4	11	2	17
Total	8	12	4	24

The families of children in the sample had varying experience of previous contact with the health services. *Table 2* shows the numbers of occasions on which a child from the family had previously been admitted to hospital.

Table 2: **Number of occasions on which a child from the family had been admitted to hospital**

Number of previous admissions	Number of families
None	4
1 - 3	13
4	7
Total	24

An indication of the distribution of social class in the sample is given by Table 3, which shows social class by the occupation of parents. The table includes separate categorisation of mothers where an occupation other than housewife was given, although occupation is usually regarded as a less useful guide to social class in women than it is in men.

***Table 3*: The social class of parents based on occupation**

Social class based on occupation	Fathers	Mothers (where an occupation given)
I	3	-
II	5	5
IIIM	8	-
IIIN	2	4
IV	3	3
V	3	-
Total	24	12

Categorised on the basis of OPCS (1991).

The length of admission of children in the sample is summarised in *table 4*.

Table 4: Length of admission

Length of admission	Number of children
Up to one week	12
Between one and two weeks	8
More than two weeks	3
Not known	1

The length of time between discharge and interview is summarised in *table 5*.

Table 5: Length of time between discharge and interview

Weeks since discharge from hospital (approx.)	Number of families
2-3	14
4	6
5-6	3
Not known	1

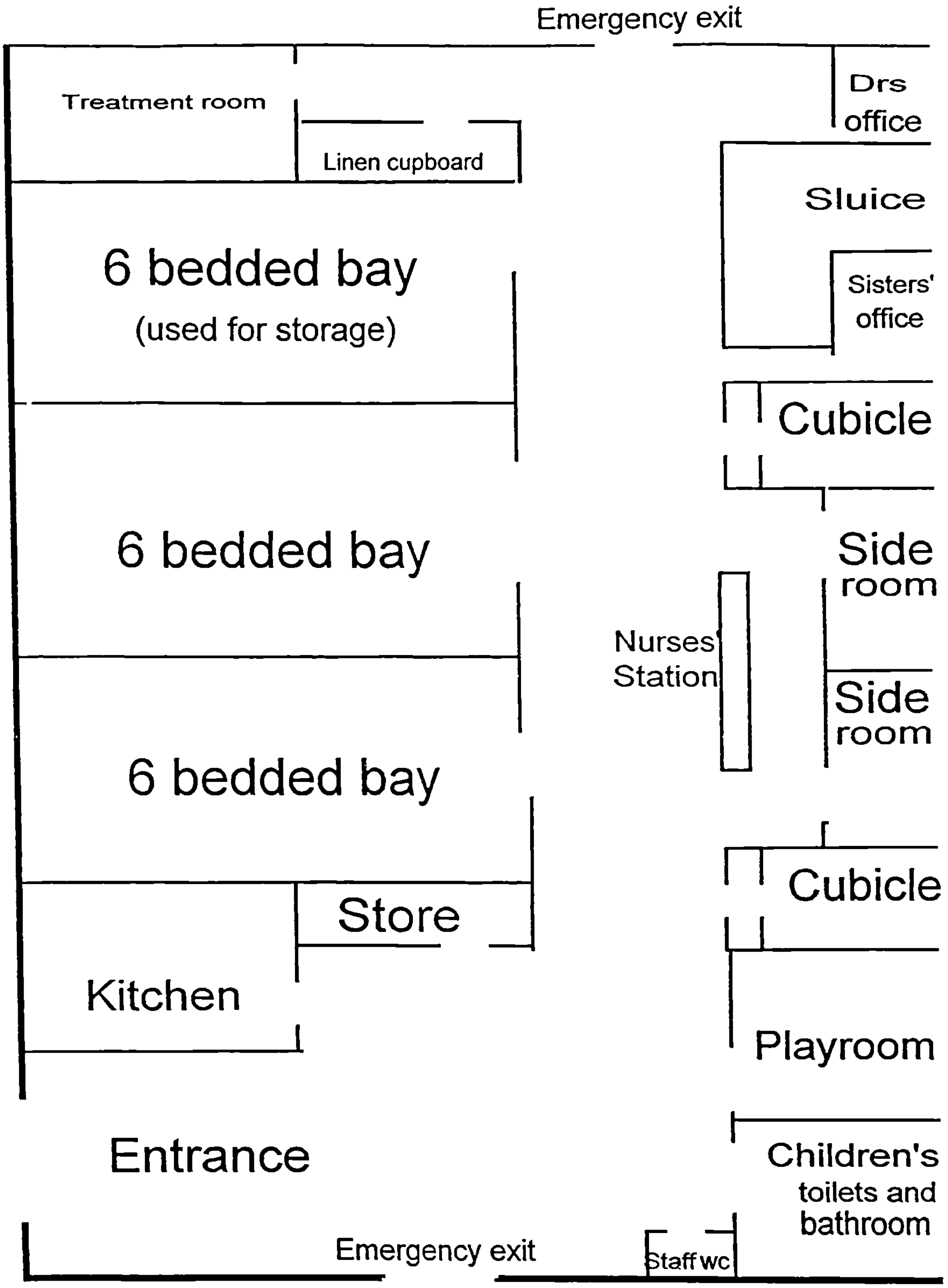

Figure 1: Diagram of the study ward

The ambiguous role of parents in the hospital

In addition to the details about the ward and study sample another important feature of the study context is the ambiguity of the role of parents in the hospital. The facilities provided for parents indicated that parents did not have the status of workers in the hospital, although they contributed to the work of caring for their children.

Unrecognised workers

The denial of privileges granted to other hospital workers illustrated the lack of recognition of mothers as workers within the hospital, for example the canteen offered a substantial discount to members of the hospital staff but parents were required to pay the full price for their meals. One couple did manage to obtain the staff discount but this was because they were able to produce evidence of their employment as nurses within another health authority.

Parents who did not go to the canteen for all their meals would have to decide where to eat the food and drink that had been brought in by family and friends. For those in side-rooms the choice was obvious because the territory was their own. For mothers on the open ward the answer was not always clear. This mother's comment indicated the problem that finding a place to eat and drink presented:

> Mother: At first I didn't have anything in the day at all, I used to wait. And, like, I had a bath in the morning so I'd take my sandwich to

> t'bathroom in t'morning. Before I go in the bath I'd have a sandwich and a cup of coffee ... And then I'd go without throughout the daytime for the first two days. And then I seen somebody else eating, so I says to him "Well I'm going to eat when the kids are eating like". So that's what I did, when they had their meal, I had my meal after that. And nobody, nobody said anything. But the point were, had you been told in the first place, you'd feel more comfortable about eating. I felt as if I daren't eat because I weren't supposed to eat.
> Int. 24:20

It is difficult to imagine any other workers tolerating such working conditions. The mother's comment that she felt she was not supposed to eat suggests that her self-esteem and confidence were undermined and that she felt that she did not have a recognised place in the hospital. Her account also indicated that she gradually discovered what was and was not acceptable. Similar uncertainty about what was acceptable was experienced by parents when they were involved in caring for their children. The ward kitchen door had a handwritten "Staff Only" notice and so parents felt that they were excluded from the kitchen. However, the rule was flexible. It appeared that parents could be allowed in to the kitchen at the discretion of the nurses. This father explained how he was given permission to use the kitchen:

> Father: ...When they first started with the measures of water, er, with it being so warm, it were horrible tasting water anyway but it soon got warm and aired this water. So I used to say "Could I have some more water?" but they must have fetched a jug three or four times before one of 'em said "Well, if you just like to nip into the kitchen area", 'cos you see it said "Staff Only", well I didn't like just walking in..
> Int. 47:47-8

The father's comments suggest both that he was given permission as a result of the work that was created by nurses collecting the water and also that he felt uncomfortable because he neither wished to demand the time of nurses in a task that he could easily do himself nor did he wish to break the rules as expressed by the notice. The uncertain position of unrecognised worker left parents unclear about what was expected of themselves and of what they could expect of nurses.

Inadequate facilities

A professionally manufactured "Staff Only" notice was displayed on the door of the staff toilet. The instruction appeared to be observed more strictly than the notice on the kitchen door. During participant observation I did not see any parent use this toilet and none mentioned it when I asked which they had used in interviews. Parents whose child was in a self-contained room were able to share their own child's bathroom and toilet but the majority of parents who were in bays on the open ward did not have such access to toilets and bathrooms. Their options were either to use the communal children's bathroom and toilets or to leave the ward and use visitors' toilets or a bathroom and toilet in the parents' unit. Both options required parents to leave the ward, which they were often reluctant to do until a visitor arrived to stay with their child. This meant that parents had the choice of meeting personal needs at times when a visitor was present to watch over the child or taking what some felt to be a risk in leaving their child unattended. Users of the parents' unit complained that the bathroom could not be locked and that the bath did not have a plug. Those parents who did not leave the ward could use the children's facilities but this meant that they would share with children and adults of both sexes. Fathers in particular found this problematic because they were embarrassed to share the facilities with a group of women and children.

The provision of toilets and bathrooms therefore gave parents the message that they were not an essential part of the workforce unlike the staff who could not be spared from the ward and so had their own toilet.

Although mothers were encouraged to stay in hospital, they did not have automatic access to basic facilities. Even the provision of a bed could not be guaranteed. The ward had a small number of fold-up beds for parents but nurses and parents both reported that at busy times these were inadequate to meet the demand. This mother's account indicated that parents felt that they had to compete with each other for the available beds:

> Mother: ... they actually got me a mattress on the floor the first night. And from then on I had a 'Z' bed which I fetched out at a specific time each night, but there was only two beds for that whole entire ward. So it was a case of, er, first come first served. You either got a bed or you didn't, or the rest of the mums sat in chairs or laid in chairs, or whatever. But it was a case of you fend for yourself. If you want a bed you go and get it. You had to ask first, but if you asked before somebody else, you got the bed.
> Int. 24:21

Dedicated facilities

There was a separate parents' unit available which included bedrooms lavatories and washing facilities. Space was limited and so rooms were not always available. Mothers often said they preferred to be with their child and felt too far away if they were in the parents' unit.

Those mothers who did stay in the parents' unit did not speak highly of the accommodation. One problem was that they disliked sharing a bedroom with another mother:

> Mother: ...you had your own bathroom and your own shower, you know, that were really nice, that were great, but it were the fact that you were sharing wi' a total stranger, that, that's what really put me off...before I went into t'bedroom she were like sat in t'smoke room and all she kept saying were "I hope you don't want window open all night", you know, I thought "Oh God", "I hope you're not gonna be coughing all night", you know, like going on about somebody that had been sleeping with her t'night before... I felt out of place really, because, I thought, well you know, she's had that bedroom all week, then I'm going in...
> Int.48:9

Because the rooms were shared mothers were expected to leave their doors unlocked:

> Mother: I weren't told I was supposed to share with somebody, they didn't come and tell me, they said I'd be in a room on my own. And I locked t'door and like somebody tried door and heard voices saying "Oh, I thought this room'd be free" and they come to see me next morning to say I should have shared with somebody, and she never told me. So t'next night I went to bed, got him to sleep, went to bed, I didn't lock it and somebody come in...
> Int. 38:20

It is not difficult to understand the feelings of insecurity that mothers felt when asked to sleep in a room that they could not lock. Mothers were both unhappy about not being able to lock their room and about having to share a room with people they had never met before.

Untrustworthy workers

In addition to inadequate facilities the ambiguous role of parents was also reinforced by the lack of trust shown in them by the hospital. Parents were not allowed to have hot drinks on the ward because there was a concern that children might be scalded by hot drinks. This rule did not apply to staff, who had a kettle in their office and often took tea or coffee breaks in there. Mothers and nurses reported occasions when the rule was relaxed for parents, usually at night although parents in side-rooms were also allowed hot drinks. The ambiguous status of mothers as unrecognised workers was reinforced by this rule because nurses were allowed to have a hot drink on the ward but mothers were not. Mothers might be workers but they were not workers who could be trusted with hot drinks. Similarly the hospital did not trust mothers to provide food for their own children:

> Nurse: That's a recent one actually, that they're not allowed to bring food in from outside and give it to their children...the reason is that they're saying that, because the child's in our care... if a food thing broke out, obviously if the child had only been eating our foods, that we know where the source had come from...
> Int. 35:14

This ruling that mothers could not bring food in to the hospital suggests that it is context rather than task that determines whether mothers can or cannot be trusted. In the private domain of the home there would be no question that providing food would be seen as the mother's responsibility and her competence to fulfil this role would usually be assumed. However, once in the public domain of the hospital even the most fundamental of maternal functions was open to question and mothers were assumed to be untrustworthy providers of food for their children.

Mothers commented on how they often relied on each other to watch over their children when they went for breaks and so demonstrated their trust in each other. In a sense mothers were behaving like good neighbours. Just as one might trust a neighbour with one's child in an emergency, these mothers trusted each other to watch over their children while they were away from the ward. However, nurses felt uncertain about contact between children and other mothers. A support worker said that she could understand why another parent might pick up a crying child but despite this felt that she had to discourage such behaviour:

> Support Worker: ...And I always feel a bit awkward saying to 'em "You're not allowed to pick other children up" sort of thing, because, I mean, I, I know it's my job here, but I'd go and pick every kid up in the bay [...] Whereas why should I and not them? [...] I usually go to 'em and say, er "Do you mind not picking the baby up because, you know, if you were to drop him, or anything, you know there's too many forms to fill in". [laughs] You know, "We'd be for the high jump because you aren't, you're not supposed to pick the babies up"...
> Int. 34:10

Although mothers made informal arrangements with each other to supervise each other's children, there was ambiguity about when it was acceptable for a mother to touch a child other than her own. The lack of trust of mothers as workers can be explained by considering the mechanisms by which official workers are employed. Mothers are self-selected workers who have not been through the appointment process. They have not signed contracts of employment and cannot be required to report for work. Mothers are not subject to any formal disciplinary framework. Mothers may be workers but they are not employees. However, the effect of inadequate facilities and the untrusting attitude of the hospital was to give confusing messages to mothers about how welcome they were and what the expectations of them were. Mothers' comments suggested that the poor facilities provided for them undermined their sense of self-esteem and left them uncertain about their role in hospital.

CHAPTER 4: SHARING THE CARE:
THE DIVISION OF WORK BETWEEN NURSES AND MOTHERS

Introduction

The division of the work of caring for a hospitalised child is important to developing an understanding of the experiences of both parents and nurses. The way in which the work of caring for the child was divided influenced parents' experiences and suggested that the parental contribution was seen by parents and nurses as essential to the safe care of children. Surveillance of children during their recovery was an aspect of care where parents were of particular importance to nurses, who felt themselves to be over-stretched. It was notable that the work of caring for hospitalised children was shared between two groups of women, nurses and mothers and naturalistic assumptions about the care of children were evident when mothers discussed whether nurses who they had observed caring for children were mothers themselves. There was little evidence of explicit discussion about the division of work between nurses and mothers but they shared a common-sense understanding of differences between maternal and nursing care. Similar common-sense understandings of the differences between the two forms of care have been described before (Casey, 1988; Darbyshire, 1992; Dearmun, 1992). However, the distinction between the work of nurses and mothers cannot be satisfactorily explained by examination of the tasks undertaken by nurses and mothers because there was considerable overlap. A more useful distinction is between the purposes of nurses and mothers.

Common-sense understanding of differences between maternal and nursing care

A common-sense understanding of a distinction between maternal and technical care was shared by the nurses and parents in the study. Maternal care was described as the everyday care that a mother would give to her child at home and included both emotional and physical elements. Technical care was the care that arose from the treatment of the child's medical condition, in the case of the study ward this was predominantly the care associated with the surgery that the children underwent.

The most obvious way to separate maternal and nursing care is on the basis of tasks because these are visible but this is an artificial separation because it reduces the experience of care to a number of fragments that do not describe the full meaning of the phenomenon experienced by those involved in care. For example, when a carer washes a child in hospital the purpose of the carer may be as much to give emotional support to the child as to ensure the child's hygiene. In addition when the division of labour between maternal and nursing care is examined it is clear that the two overlap because mothers can be involved in skilled technical work and nurses can give the everyday care associated with mothers. It is therefore not possible to distinguish between maternal and nursing care by identifying the tasks performed by mothers and nurses. A more useful distinction is between the purposes of mothers and nurses because while the same task might be undertaken by both groups, there would be important differences of purpose for doing the task which distinguish between nurses and mothers. It is also important to consider the circumstances in which care is given. There appeared to be a shared understanding amongst nurses and mothers that the contribution of parents to care was essential both because of the relationship between parent and child and because of the lack of nurses to care for children without the essential contribution of parents.

“Parents” and “mothers”

Maternal care was understood in a naturalistic way by both mothers and nurses, which was evident both in the assumptions of nurses that mothers’ wished to be involved in care and in the attitudes of mothers to nurses who were or were not mothers themselves. Although fathers were involved in the care of children, their role was as a substitute mother or as an optional extra. For this reason the term “mother” is used to describe the parent who stayed in with the child for longest and was most closely involved in the care of a child. This was nearly always the mother and when a father undertook this role there were particular contingencies that had led the family to decide to substitute the father for the mother. It is therefore misleading to discuss “parents” because the term disguises the different roles of mothers and fathers in the care of their children.

The work of nurses: “medical” care

Mothers shared a common-sense understanding about the distinction between maternal and nursing care. They differentiated between their own contribution to care and that of nurses by using the term "medical" to identify the specific work of nurses. The identification of nurses with the special care needed when a child was treated for a medical problem implied that the work of mothers was the everyday care that remained:

> Interviewer: So what did you feel responsible for when you were in?
>
> Mother: Just generally, I mean his medical care was in their hands, but to keep him happy as such and as settled as possible, I felt that was my responsibility.
> Int. 20:8

Descriptions of nurses' post-operative care of children indicated the nature of the work that mothers saw nurses doing, for example the measurement of physiological signs at regular intervals:

> Mother: after she came back from t'theatre, every half-hour for her blood pressure and her temperature, and they were coming in every half-hour, then every hour, then it dwindled down to every two and then it were every four.
> Int. 30:9

The implication of the gradual increase in the intervals between nurses' measurements of physiological signs was that responsibility for observation of children was transferred from nurses to mothers. In addition to physiological observations, there could be infusion machines, drains and wounds to attend to:

> Father: the student nurse'd come in and they'd take her temperature and put it down on her chart and then they'd take the, write down t'sort of, what this saline thing were doing like, you know.
>
> Mother: They were measuring that weren't they?
>
> Father: And, er you know, they used to come in a morning, monitor t'morphine..

> Mother: Emptying her drains, (Father: Aye, and, and..) weren't they, and measuring that
>
> Father: ..measuring t'water content that she'd passed and you know, charting t'colour of the urine what were coming through, you know. And, you know, they'd say "Oh well, this is get-, you can see she's getting better, this, this fluid's clearing"
> Int. 47:18

Mothers assumed that nurses should place priority on medical tasks and that mothers themselves could help by freeing the nurses from the burden of children's more everyday needs:

> Mother: I think, well, parents really **should** look after t'kids, I think, nurse is just there for, you know, medical reasons.
> Int. 33:13

The understanding that the primary responsibility of the nurses was for medical care was shared by nurses although the term "technical" was substituted for "medical " when nurses described this work:

> Nurse: and we just, if they [a parent] stay in, we just do the technical things, checking the drips, reading the drips, doing their obs and everything and hope that the parents'll do all the hygiene, feeding, whatever need that the baby does, with our help or us getting the feeds or whatever.
> Int. 21:17

Although the language differs it is clear that nurses were describing a similar range of tasks to those identified as "medical" by mothers. It is not surprising to find that nurses avoided describing their work as "medical", a term that would be politically incorrect for nurses to use in a description of their work since nursing is continuing to attempt to establish its credentials as a profession in its own right, independent of medicine.

It is not surprising to find that nurses placed more emphasis on the "technical" or "medical" care associated with the treatment of children's medical problems. The first priority of nurses, mothers and fathers will always be the safety of children in hospital. However, this is not to suggest that the focus of nursing attention on these aspects of care was seen as entirely satisfactory by all nurses and mothers. When nurses explained their concentration on "technical" care, they expressed dissatisfaction with the limitations of this role and the service that they were able to provide to families:

> Nurse: it's not so bad now, but when it gets very short staffed we rely a lot on our parents doing our basic care and us just doing the technical stuff, because that's all we have time to do.
> Int. 19:9

Thus tasks were seen in terms of a hierarchy, with technical tasks having high priority in the work of the nurses and other care having lower status. When the nurse described "our basic care" the ownership that was described was half-hearted because this was work which could be left to "our parents" to do, The term "our parents" implies ownership of a workforce who could undertake the low status work while nurses concentrated on the "technical" elements of children's care. The priority given to "technical" care reflected the purpose of the nurses, whose first concern was to ensure the safety of children before and after surgery.

Maternal care: emotional support of the child

Mothers saw their role as supplementing the "medical" care of nurses with emotional care that complemented nursing care. In this quotation it is a father who stayed in hospital because the mother was breast-feeding a new baby at home who described this emphasis on emotional care:

> Father: I suppose we saw ourselves really, you know, looking back, as providing the kind of, the emotional and personal support to Luke to back up their, their medical care. (Mother: Yes, back them up)
> Int. 26:25

The idea that mothers can add an emotional dimension to the care of hospitalised children was central to the Platt report (Ministry of Health, 1959) where it was recommended that the mother should be admitted with her child for this purpose. It is the relationship of mothers and fathers with their children that makes their contribution to care unique:

> Mother: I did feel, if I hadn't been there I don't, well, personally I don't think that Fiona would have settled down for the nurses as she would for me. I would hold her hand and say "Shhh, Mummy's here" and she would grab her comforting blanket and the thumb would go in and she would settle down again after she'd got over wanting to do a wee or whatever it was that was bothering her.
> Int. 45:7

The sense of threat that parents associated with the hospital environment was illustrated by the emotive term "stranger" which was used to refer to hospital staff:

> Mother: Mm, and Julie's not one for strangers anyway.
> Int. 30:3

Parents were concerned that having to form relationships with "strangers" would be stressful for their children:

> Father: He's never yet woken up in an environment where everybody is really a stranger, even though they're friendly
> Int. 36:7

The use of the term "stranger" is interesting because it is such an emotive term in the context of adult - child relations. Children are warned about the perils of "talking to strangers" both by parents and by other adult advisers. The comments of mothers suggest that hospitalisation required children to breach this important rule:

> Mother: I mean you know a child, it responds better to someone it knows, than somebody who is a total stranger. I mean Alison is a very shy child, she would never talk to a stranger
> Int. 24:30

"Strangers" in the world of the child are mysterious and threatening. The use of the term by parents is suggestive of a sense of threat as well as of unfamiliarity, particularly as the explanations of the dangers of strangers that are offered to children usually include exemptions such as police officers. It is therefore surprising that nurses were included in a category with such negative overtones. The choice of this pejorative term suggested that the hospital environment was seen as threatening and challenging by parents and helps to explain the importance that mothers and fathers attached to providing emotional support for their children.

Mothers' involvement in the physical care of children

The presence of parents in the ward with their children naturally led to their involvement in the physical care of their children. Nurses stressed the importance of parental involvement in the care of children and presented it as a continuation of the care that the parent would give at home:

> Nurse: I think we usually let the parents do as much as they can, and if there's any technical things then we obviously teach them, watch them doing it until we feel they're confident to do it. And that they can do the normal day to day caring that they do at home, changing nappies, bathing, feeding. If they're happy to do that then they just carry on while they're in hospital...so that you don't cut the parents out completely, they still feel that the child's theirs and they're helping to make them better.
> Int. 18:1

The emphasis given by this nurse to parental control and to the continuity of parental role was echoed in other nurses' comments. There was less emphasis given to the significance of parental involvement for children's emotional well-being than to the benefits of involvement for parents themselves. The emphasis given to parents' rather than to children's interests is surprising since the basis for the Platt committee's recommendations (Ministry of Health, 1959) was concern about the emotional welfare of children rather than that of parents. One explanation might be that the value of parental involvement to children was taken for granted and so was assumed to be understood without further mention. Alternatively the close proximity of parents who are usually regarded as the consumer of health care services for children meant that their concerns had higher priority for nurses than did their assessments of the emotional needs of children. It was assumed that the parents' wish to be involved in care complemented children's preferences:

> Nurse: most of them want to look after their children while they're in hospital and the children want the parents to look after them and not the nurses.
> Int. 21:17

Although the purpose of involvement was emotional care, in practice emotional and physical care cannot easily be divided into separate tasks. Thus their involvement in care for the purposes of supporting their children meant that mothers were undertaking tasks that would otherwise have to be done by nurses. The close relationship between emotional and physical care is illustrated by a mother whose comments also indicated that the distinction between "basic" and "technical" care belies the skilled care that mothers gave to their children:

> Mother: I couldn't let a nurse do it [give medicine to the child]. She'd spit it out at 'em, I know my daughter, I know how to just get it down the back of her throat [laughs].
> Int. 30:21

Thus the tasks carried out by parents and nurses could overlap and mothers could be involved in tasks which might be categorised as nursing work. The distinction between nursing and maternal tasks is further confused because there were occasions when mothers were taught tasks which were the responsibility of nurses in hospital, so that the child could be discharged to home where technical tasks would become part of the everyday routine of maternal care. The distinction between maternal and nursing care is clearest when viewed as a distinction between different purposes rather than different tasks. Nurses were responsible for ensuring effective and safe care of children undergoing surgery and so their principal purpose was to ensure the safety of children. Mothers described themselves as staying with their children in order to support them through a strange and difficult experience and so their purpose was principally to give emotional care to their children.

Maternal care: naturally women's work

Most of the resident parents were mothers. When fathers did stay alone there were particular contingencies that had led to the decision:

> Mother: ... with Mark being three month old, I was still feeding him, he was too young - erm, OK he could have gone straight on the bottle, but erm, I actually felt he was too young to have a complete break from me. Erm, so it was just natural for you [to husband] to have time off work to go with Luke wasn't it? And I commuted in the day once we'd got his Grandma and Granddad here.
> Int. 26:7

Work commitments were cited by some families as the reason for fathers not staying in with the child. However, the primary role of mothers as child carers appeared to be the principal reason there were few fathers in the hospital. Even where the father was able to take time off work and live away from home this did not guarantee that he would stay at the hospital. Julie's father took time off work and stayed with relatives who lived in a town near the hospital. He used the time off work to make travelling to and from the hospital easier as Julie's mother explained:

> Mother: ... he put a week's holiday in so he could be with, near me and Julie.
>
> Interviewer: so [...] he stayed at Nearbytown and came in to you did he?
>
> Mother: Yes, yes, it's a lot easier than coming home here, going back every day.
> Int. 30:4

Daniel's mother described how Daniel's father fell asleep in the playroom when he came to the hospital and suggested that fathers would not be actively involved in their children's care:

> Mother:...some people'd say "Oh, isn't he awful, making you go all the time?" and you'd say "Well to be quite honest it's better if he don't go". And I found other parents find that their husbands, or mothers found that it was like left to them because their husband's like useless. You know, they just sort of did nothing, moaned and tutted.
> Int. 31:20-21

Daniel's mother also had an explanation for the predominance of mothers in the ward:

> Mother: If you looked in the hospital, it was nearly all mothers that are there, that have to stop. I mean, yes I know the fathers are bread-winners, but you know, even at weekend and things.
>
> Interviewer: Why do you think that is then?
>
> Mother: It's just a case of the 'mother' ideology, isn't it, mothers should stop with their kids.
> Int. 31:21

Fathers as substitute mothers

Where it was the father and not the mother who stayed with the child the father was acting as substitute for the mother because of particular contingencies. The mother was breast-feeding another child, or ill, or had tried to stay in with the child and found herself unable to cope with being in hospital.

Fathers also acted as temporary substitutes, relieving mothers for a variety of reasons including meals and rest. A nurse suggested that fathers also stayed in order to give mothers respite during longer hospitalisations:

> Nurse: ... because we do get a fair few dads stopping actually, especially if they're in for a while, t'mums swap over, take it alternative nights...
> Int. 37:17

The father who stayed in as a substitute mother was regarded as being in a strange world:

> Support Worker: I always feel sorry for dads that stay on their own because all t'other mums stay, and I sometimes wonder if they feel a bit out of it, you know, because everyone else is female looking after t'kids, and, you know, but some dads are really good, you know, they're just as good as t'mums.
> Int. 34:24

For this observer at least different standards applied to her judgement of mothers and fathers. It appeared that a father who was just as good as a mother was a "really good" father. The care which a mother is naturally qualified to give cannot be expected to come naturally to fathers and so like Dr. Johnson commenting on a dog standing on its hind legs the wonder is not at how well the thing is done but at the fact that it happens at all.

The words "parent" and "mother" were often used interchangeably by mothers, fathers and nurses although it also seemed to be assumed that it was natural for the mother to be the parent who stayed in hospital with the child and fathers who stayed were either an extra resident parent or substitutes for mothers. This is not surprising because the central place of mothers in family health care has been documented in the sociological and feminist literature. This pattern is summarised by Graham's (1984:180) comment that

> "family life, in its literal and symbolic sense, depends on the unpaid work of a parental caretaker. It depends primarily on *women's health work*. The vitality of most families rests on the fact that, despite their increasing involvement in income production, women continue to meet the health needs of their partners and their children."

Mothers, then were the "natural" carers for children. This notion of "naturalness" had consequences both when nurses substituted for mothers and when the circumstances of care changed, following surgery, when mothers could find a conflict between their "natural" response to the child and the requirements of post-operative care.

Nurses as substitute mothers

In addition to their responsibility for "medical" care, nurses substituted for mothers when they were not able to be with their children:

> Interviewer: So I mean what did you see the nurses as being there for?
>
> Mother: Back up if anything happened [...] basically as back up for when I wasn't there, or for if something went wrong.
> Int. 31:32

The substitution provided by nurses was regarded by parents as a limited resource which meant that only a minimal service could be expected that was inferior to care by mothers themselves:

> Mother: I'll never question the quality of the care in a medical sense at all, but you're into the realms of, you can't, I don't think you can expect nursing staff to wander up and down, erm, cradling your baby trying to get it off to sleep. The practical matter is, he'll probably have to cry a bit, whereas you'd be walking it up and down because you're the parent.
> Int. 26:14

The main purpose of the Platt recommendation that mothers should be admitted to hospital with their children was to supplement the nursing care of children by ensuring the continuity of the mother-child relationship (Ministry of Health, 1959). This was an important element in the purpose of mothers who stayed with their children on the study ward. However, mothers also stayed because they were concerned that nurses would not be able to provide basic substitute care for their children. There were concerns about the availability of nurses should children become distressed and about the quality of emotional care that nurses could give. The expertise of nurses in providing emotional care to children was an unknown quantity and there was reluctance to put it to the test:

> Mother: I did think that perhaps towards the end of the stay, erm, if she seemed as though she was going to sleep through the nights, then I would perhaps go and stay in the rooms [away from the ward]. But I didn't, I didn't do that because every night that we'd been there she'd been awake two or three times and, erm, I'd settle her down. I don't know whether the nurses would have been able to settle her down, but when she did wake she was always crying for mummy.
> Int. 45:4

Fiona's mother summed up these doubts about substitution by expressing concern that her child would have suffered if she had not stayed with her:

> Mother: she would just have sat there, erm, and waited for them to go to her, and I don't think they would have gone as regularly as I would have expected them to.
> Int. 45:35

In addition to the limited availability of nurses, the quality of substitution also concerned mothers:

> Mother: [a student nurse] did come and stay with him. But er, he was in a state, I mean he was standing up and trying to climb out by the time I got

> back and I'd only been gone a few minutes [...] she was sitting right there watching him climb over the rail [laughs].
> Int. 46:26

Children need time to build up trust in new carers and if substitutions for the mother are occasional, for example only when mothers go to the canteen for a meal, the task of the substitute mother is more difficult than if she can first establish a relationship with a child. Skill is therefore required in substitutes but mothers found that it was usually inexperienced student nurses with limited skills who were the nurses available to substitute for them. Mothers noted that few of the nurses were themselves mothers and suggested that this explained the way in which they cared for children:

> Mother: I can honestly say I didn't feel, although they would get children on their knee and nurse them and play with them and do things like that, there was just something about them that made me think that they weren't mothers themselves.
> Int. 45:30

Those nurses who were mothers were thought to be noticeably different:

> Mother: I think the way they talk to the children, er, I can't really put my finger to it, but little things that they know. Like I saw one, er, nurse [...] and at night time she'd go round settling them all down and she'd actually kiss them night-night you see. I don't think you'd get anybody who hasn't got children doing that. But I know she's a mum anyway
> Int. 44:11

Mothers described skilled care of children in naturalistic terms, arising from experience rather than from education or training:

> Interviewer: my job's teaching people to look after children and parents, and do you think there's anything that I should be teaching them that would help?

> Mother: Er, it's difficult to say really. Because, before I had children, I didn't really know much about children, do you understand what I mean? [...] And I've only really gained experience from having my own children because you sort of get a feeling as to what they want, if you understand what I mean.
> Int. 44:20

In this mother's view maternal care was not something that could be taught, it could only be learnt through experience. The care of children was cast in naturalistic terms making effective substitution for the mother very difficult for nurses who were not themselves mothers. Such concerns can only have added to mothers' reluctance to leave their children and go to the canteen for a meal or a drink or simply to get away from their child's bedside for some time.

The argument for the psychological benefits of parental presence and involvement in hospital care emphasises the irreplaceability of the parent. One consequence is to make it more difficult for student nurses to gain experience of everyday care of children. A staff nurse complained that she had been unable to arrange for a student nurse to practise bathing a baby during her allocation to the ward. The physical care of children which was traditionally done by student nurses is now the work of mothers and so there are fewer opportunities for student nurses to learn the skills of maternal care through experience. In future it is possible that mothers will increasingly encounter nurses who lack skill in the everyday care of children unless either the work-force includes more mothers, or nurses have other opportunities to learn the skills to meet the everyday needs of children.

Maternal care and circumstances

One way of distinguishing between maternal and technical care is to consider the different purposes of mothers and nurses, so that even where the same task is performed, differences between maternal and nursing care can be identified. In addition it is necessary to take account of the circumstances within which a task is performed. For example after surgery simple, everyday tasks can take on new meaning:

> Mother: I didn't like to touch him at first, you know with all his tubes on, and I didn't know what to touch and what not to touch. They changed his bum for t'first couple of times
> Int. 33:15

As with other physical care, parents had not usually given much thought to what they would and would not want to be involved in before the event. They faced their involvement in the physical care of their children following surgery unprepared:

> Mother: No, I hadn't thought about anything like that and the first morning, erm the beds were being changed, and I said Ha- can I strip her down and give her a good wash and brush her hair and...everything else?" They said, "Oh yes, but if you don't want to we will."
> Int. 45:16

It is difficult to imagine how a mother could react to this response with anything other than an agreement to wash her child. The question "if you don't want to" constructs "not wanting to" as the exceptional response. In the public world of the hospital ward the moral character of the mother is on display (Darbyshire, 1992) and so it would be difficult for the mother to respond that she did not want to wash her child. A refusal would breach the convention that a mother naturally wants to care for her child and so bring into question the mother's moral competence. The question established a choice between wanting to wash the child and not wanting to wash the child: there was no explicit offer of assistance or support in the question. The mother went on:

> Mother: I got her face done and her top half done and then it came to, er, all the baggage and everything down below. And I, and I was just a bit wary of doing all that and I said "Well, how close should I get? or can I wipe all her..." "Yes, it doesn't matter, as long as you don't use all these smelly potions round it, just use the water and everything."
> Int. 45:16

Handling of a child after surgery was regarded by some parents as a skilled activity and not just a continuation of the everyday care that a mother would be expected to give a child at home. The skills that have been acquired naturally through parental experience did not always equip a parent to care for a child who had undergone surgery:

> Father: I was very tentative about holding or lifting him..
>
> Interviewer: Because of the tubes?
>
> Father: And also being aware that the incision was under the arm, now they're expert at lifting from the bottom, and I was still quite nervous for the next day or two when he was back on the ward, doing that. So at that point I think they did more lifting, nappy changing [...] simple things like changing the sheets, you know they do it with remarkable efficiency and, er, yes, you know, so I suppose I saw then well it isn't hurting him to move him and this is how to do it.
> Int. 26:12-3

It is intriguing that this father's account differed from those of mothers when he reports that nurses doing everyday maternal tasks. An interesting question which the comparison of these accounts provokes but does not answer is whether less competence was expected of men than of women in the maternal care of children. However, the number of fathers closely involved in care on Studyward was small and so it is not possible to draw conclusions from the father's comments.

Following surgery, children could present their parents with urgent needs:

> Mother: I could hear her shouting "Mum, mum" and I'd just nodded, you know when you just feel yourself going? But at the same time I've got a bad back and I sort of leapt out of bed and went flying across the room and Angie's saying "I'm gonna be sick, I'm gonna be sick" and I'm trying to grab a bowl, because she wanted, her reaction was to sit up, well my reaction was "She's sitting up too quickly" because of the operation she's going to hurt herself and there's all these tubes and everything. But her reaction was "I'm gonna be sick: sit up" so she were trying to fight her way up, I'm trying to support her, hold the bowl, Angie's got really long hair down her back which they'd untied to go to theatre because of all the metal clips for the machinery. So all her hair was going all over, I'm trying to hold that, hold her, hold the bowl [laughs] so, I went to fetch t'nurse once she'd been sick.
> Int. 47:10

Tasks which seemed before an operation to be the natural role of the mother took on a very different character after the child returned from the operating theatre. Attending to a child who is vomiting in the night is an example of a task that a parent would expect to undertake at home but which becomes more complicated and concerning when the child is encumbered with equipment and has a surgical wound. Angie's mother did not stay in the hospital after the first post-operative night as she had intended, she visited during the day and her husband took time off work to stay in the hospital with Angie. This was explained in the interview as partly because of her painful back and partly because she felt that she could not cope with staying in. It would appear that the common-sense understanding about what the nature of the distinction between maternal and technical care did not work for Angie's mother. She found herself in a stressful position which resulted in her changing her plan to stay with Angie in hospital. It appeared that Angie's mother had been committed to staying in the hospital because she arranged time off work and prepared enough meals for the freezer to feed the family until Angie was discharged. Angie's mother found that the demands of continuing everyday maternal care in the circumstances of the immediate post-operative night were more than she could cope with.

Conflict between normal parenting and the demands of the hospital

The circumstances of care during post-operative recovery could result in conflicts between the norms of everyday maternal care and the demands of care in hospital. Eating and drinking are important components of maternal care and continued to be the responsibility of parents even when the circumstances of illness and treatment changed the nature of this care. Following surgery some children were reluctant to drink and this was a concern for the nurses as they observed the post-operative recovery of the children. However, the responsibility for ensuring that children continued to drink appeared to remain with the mother:

> Mother: she seemed to stop drinking. Erm, which panicked me, and the nurse kept saying to me "She really must take in more fluids, she must take in more fluids or the drip will have to go back up"
> Int. 45:24

The need to persuade children to drink resulted in parents believing that they had to adopt a firm line with their children:

> Father: when the nurses told him [the child, Alec], told us he wasn't drinking enough and if he didn't start drinking they'd have to put his drip back, now like I didn't want to upset Jane [Alec's mother], so Jane went down for a drink and I explained to Alec that if he didn't drink and eat, the nurses would have to come back and put the needle in his arm again
> Int. 22:18

This need to be firm with the child resulted in parents experiencing conflicting feelings, on the one hand they had come to the hospital in order to try to limit the emotional distress experienced by their children and perhaps even to act as an advocate and protector of their children but on the other they found that they needed to force their children to comply with the demands of the hospital. While involvement in the care of children in hospital was described as "natural", it could result in parents finding themselves in conflict with their natural wish to protect their children from distress. The responses of Angie's sisters to her father's chiding illustrated conflict between the demands of hospital and those of families:

> Mother: but Sarah [sibling] found it upsetting didn't she? And Sarah, if Sarah had been there when Robert [father] were saying "Well if you don't drink you'll not go home" or "You'll have to get out of bed and sit in t'chair", if Sarah'd have been in there when Robert were being sharp with her for her own good, Sarah would have been the first one to say "Yeah, but she's not well, dun't get on at her"
> Int. 47:31

Nurses complained that parents were insufficiently "firm" with their children. This was of particular concern when parents responded to the changed circumstances following an operation by being protective rather than actively rehabilitating their children:

> Nurse: quite often the parents will just care for the child where they find them, in the exact position, they won't deviate from what they see has already been done. So they might need some sort of a suggestion, they might be quite capable of getting the child out of bed but they need that sort of insight that that's what the child should be doing
> Int. 16:15

Mothers and fathers explained the difficulties they experienced in becoming detached in order to be firm with their children and described their distress of being involved in unpleasant procedures. These data are considered in more detail in a later chapter. What is clear at this stage is that while mothers and fathers might be involved in the same tasks as nurses, their purposes were different and the circumstances of care could result in tasks having very different meanings for parents and nurses.

Mothers believed that their contribution to care was essential

The involvement of parents in their children's care has come to be seen as important in the years since the Platt report (Ministry of Health, 1959) both in the health services and in wider public discourse. An example of how widespread is the assumption that parents should be involved in their children's hospitalisation is an article that appeared in the Sun newspaper under the headline "42 minutes - that's all Charles can spare for Wills (Dampier and Verity, 1991). The article condemned Prince Charles for spending what the Sun newspaper considered to be an inadequate amount of time with his son who had been admitted to hospital after being struck on the head by a golf club at school. The fact that the Sun newspaper could use this line of argument to attack Prince Charles indicates the widespread popular assumption that parents should be with their children in hospital as well as the enthusiasm of the newspaper to use any available weapon to attack Prince Charles. Therefore, emotional support for hospitalised children is widely recognised as important and some mothers believed that their involvement in the care of their children was essential:

> Mother: someone had to keep him entertained, you know, the nurses couldn't do it all the time, and I'd feel guilty if I wasn't there.
> Int. 31:22-3

The consequences of inadequate emotional care were seen as serious and there was a belief that if parents did not stay with their children in hospital their children would suffer:

> Mother: I needed to be with him for his emotional well-being, and I am very glad that I stayed with him, erm, because I think of the under-staffing and all of that...I know other people, other mothers that have had their children stay in hospital and they have not stayed with them. Erm, the kids have nightmares and they're very clingy and if the mother walks out of the room they're screaming for them,
> Int. 46:5

These comments indicated two possible deficiencies in emotional care. One was separation from the family which could only be avoided by a mother or substitute staying in hospital. However, another cause for concern was the emotional care available when a mother or substitute did not stay with their child. Mothers judged what would have been the fate of their own children through their observations of other children in the hospital. Their observations of children without parents with them suggested that there were not enough nurses to substitute for maternal care:

> Mother: he was only three, and it up- it did upset me a bit, er, and they couldn't come and visit him quite as much, you know, they couldn't stay with him [...] And I'd go up and ask him if he were all right and everything. Which I suppose really the nurses and staff they don't have time to see to individual children all the time, but I think he just could have done with a little bit more attention because he hadn't got his mum there you see. But, er, he didn't like anybody else getting him dressed. And er he used to be really upset at those times. And I think, you know, probably somebody should have sort of took him under their wing a bit more than they did do.
> Int. 44:21

Because they were on the ward throughout the day mothers were able to assess the extent to which they could or could not expect nurses to have time to care for children whose mothers did not stay with them:

> Mother: there was a child ... whose parents didn't stay each night they were always there by half-past nine, ten o'clock in a morning and didn't leave until he'd gone to sleep at perhaps half-past nine, ten o'clock at night, but he was always awake during the night and he was always crying for mummy or daddy, but obviously at night time I was amazed on the ward how busy it was at night ... I felt that they were very good with him, they could come and if they could, if he wanted to go to the toilet, they would, erm, they would help him, but I felt that, erm, myself and there were a couple of other mums on the ward gave him, er, comfort as well. Erm, and I realised after the first night of being there that I couldn't go, I couldn't have left Fiona at all.
> Int. 45:6-7

The hesitant way in which this mother talked about the child in the night indicates the reluctance of parents to speak in a directly critical way: the mother was as concerned to excuse the nurses from personal responsibility for the inadequacy of the care available to the child as she was to highlight it. Her conclusion was certainly not hesitant: she could not have left her child, for fear that she could not rely on there being nurses to care for her. The fact that she had comforted another child herself told her that there were not sufficient nurses to do this work. Other parents described similar experiences:

> Mother: it didn't seem like there was enough staff and my husband said the same thing, didn't you? [...] I felt really sorry for the kids that were there by themselves, because there was like a little girl next door to me and she cried and cried all night for her mum and no-one ever went in to her at all. And I thought, you know "Gosh, what if I'd made the choice to leave him here by himself? Would they just have left him here to cry by himself?" you know.
> Int. 46:3

The sense of obligation and the importance attached to being with the child could tie the mother to the child and make it difficult for her to leave the child's side:

> Mother: she wouldn't let me out of her sights, I'm afraid. I mean, I found it hardest was the first two or three days was the hardest, because she wouldn't let you out of her sight
> Int. 30:5

Some families complained of the difficult behaviour of their children both in hospital and at home after their discharge and blamed this on the enforced closeness of mother and child in hospital.

However, it was not just the importance of emotional care that made mothers essential. For some mothers it seemed that their contribution was essential to ensure that their children were adequately cared for in hospital. The mother of a child who spent a period of weeks on the ward believed that mothers were an essential part of the workforce:

> Mother: I mean one nurse actually said to me, I says something about "Oh, next term," I says, it's just been half-term for colleges "I'm going to have to go in some days for College". And she says, "Well, don't worry about it, but it makes it much easier for us if you're here". You know, and so I didn't go to college because I thought, "No, 'cos she'll just sit on her own", you know [...] parents are relied on a lot to do things.
> Int. 31:17

Incidents were quoted by mothers as evidence that their involvement was essential. For example a mother described the removal of tubes following surgery:

> Mother: I knew they were going to take 'em out, and so, erm, I told my husband to be there **early.** And, erm, (Interviewer: so you were prepared for it) so we were both there, yes, and we were both holding her down while one nurse were taking 'em out, which I thought "Well, thank God I'm here: would they have had any other nurses to come if we wasn't there?"
> Int. 30:15-6

Nurses acknowledged their reliance on mothers

Mothers' care of their children was regarded as a useful contribution to the work of the ward by the nurses:

> Nurse: It's a big help, it's a big relief to know a parent's just arrived and that child's due a feed, when it is busy. It's a big help.
> Int. 23:15

The assessment of how important the work of mothers was to the ward is complicated by the difficulty of distinguishing between the tasks of physical and emotional care. In addition the question of whether the contribution of parents was just desirable or essential to the safe running of the ward was a sensitive one. The answer of a senior nurse to a question about the importance of the parental contribution illustrated a sensitivity to the implication that mothers were relied on:

> Interviewer: Do you feel that you could run the ward if they weren't doing things, or do you rely on them?
>
> Nurse: I feel we do run the ward without them. We go through spates, we go through times where a lot of the parents can't stay and then we do take on the care. And then other times we have loads of parents. I think we could run the wards but I don't think the children would be as happy as they are. [...] I mean we would do, but it's just to the degree of how well we'd do it.
> Int. 18:6

Even in this cautious response to a clumsy question that was excessively challenging, the nurse acknowledged that the care would be of a poorer standard if the parents were not contributing. Other responses were less guarded, for example this senior nurse:

> Nurse: there's never enough time, it's a big complaint of nurses, because we don't have enough staff to do what we'd really like to do, which is a shame really because I think the nursing care would be much better, we wouldn't be so reliant on the parents
> Int. 15:9

Nurses found it difficult to imagine how they would cope without parents on the ward. Children are less socially independent than adults and will need time for play which nurses believed that they did not have:

> Nurse: I mean if we had a ward full of children, erm, but there was no parents at all, to sort of entertain them and things I think we'd have a big job on our hands. I mean even though obviously they're recovering from operations and things, they still obviously need that sort of social relationship, playing and obviously erm stopping them from getting bored and things.
> Int. 35:8

A junior member of the nursing staff said that parents could not always be guaranteed that a nurse would watch their child while they went for a break from the ward:

> Interviewer: So, if they sort of come and say to you "I need to go for a drink and will you stay with him?", have you usually got time to do that?
>
> Support Worker: It just depends, sometimes you have, sometimes you haven't.[...] But half of t'time on this ward you haven't got time to sit with 'em.
> Int. 34:12

One nurse suggested that the increased involvement of parents in the care of their children had been matched by a reduction in the numbers of nurses on the ward:

> Interviewer: do you think you, you could sort of do everything you need to for the child if the mums weren't here?
>
> Nurse: No, I don't, no I don't. No. I think, I mean, I often look back on the staffing levels when I was a student on here [...] and

> yet you were always doing something. But when I look back it's
> because parents didn't seem to stay as much then
> Int. 37:19

These accounts are not conclusive evidence that there were insufficient nurses to care for the children but they do indicate that at least some nurses and parents shared a belief that the work of the ward could not be accomplished without the contribution of mothers. This shared belief affected behaviour, one example has already been discussed, which was Daniel's mother who did not go to college as she had intended, and there were others.

Surveillance of the child

Some parents at least believed that their presence was essential in order to ensure that their child was adequately supervised and that they did not come to harm because of a lack of surveillance. These mothers believed that there were not sufficient nurses to ensure the care of their children. They felt that they had to stay with their children in order to assure their safety as well as their comfort.

Some mothers said that there were always nurses available and that they were not concerned:

> Mother: There was always somebody at t'desk, or walking about in t'other ward, just tell 'em I was going for summat to eat or drink. You know, no problem "We'll look after him."
> Int. 38:24

The mother's comment is consistent with avoidance of criticism of nurses and an acceptance of her role in caring for her child. She expressed satisfaction that when she left her child she could tell the nurses and they would reassure her that she could go. This does rather sound as if she was asking permission to leave the ward. There is no hint of complaint in this mother's account: she described the experience as "no problem". However, not all mothers found that nurses were available to supervise their children and sometimes other parents were relied on:

> Mother: she was either asleep when I went, I never went unless she was asleep or the lady who had the daughter in the next bed, or the nurses with her.
> Int. 45:17

This mother's account would appear to contradict that of the previous mother: she felt unable to leave the child and relied on other mothers to watch over her child while she was gone. While it is possible to read the accounts as contradictory it is also possible to read them as consistent with each other. The first mother made little demand, she informed the nurse that she was leaving but did not ask for close attention to be paid to her child. The second mother was concerned that her child would not be left alone and when a nurse was not available to do this, she either waited until the child was asleep or asked another mother to substitute for her. It was when the expectations of mothers about the appropriate level of surveillance for their children were not met that a feeling of dependence on mothers was expressed. The particular needs of the individual child for surveillance caused mothers concern. It is one thing to ask a nurse or another mother to watch over a child in a general way but some had concerns about their children's specific needs:

> Mother: I just had to make sure that, erm, she was convinced that she'd been on the potty and then she was happy. Erm, and that she couldn't get

> off the bed. And I felt as if I hadn't been there, if somebody hadn't been there she'd have tried anyway because she's quite a determined little girl when she wants to be.
> Int. 45:31

There were different ways in which mothers felt that they had no choice but to take responsibility themselves for the surveillance of their children. It is necessary to look in detail at particular circumstances in which mothers felt that they had to take responsibility for ensuring their children's care.

Vulnerability following injury: Sharon

Sharon was admitted to the ward from a nearby intensive care ward after she had undergone brain surgery following a road traffic accident. Sharon had been very ill but made a rapid recovery. Her mother thought that she had been transferred from the intensive care ward too soon. The move from close attention in intensive care to the less controlled environment of a general ward is not always easy, it is possible for patients and their relatives to find the transfer to greater self care threatening. Sharon's mother said:

> Mother: both her eyes were closed, it had gone to the other eye, and it was shut, and I mean they were ballooned, they were out here [gestures] like little golf balls. And I'm sat at the side of her, of course I've got to go to the toilet. The minute I go to the toilet, she rears up, unbeknown to me, I mean I'm in the toilet.
> Int. 24:17

Sharon's mother returned from the toilet to find her child on the edge of the bed and was reminded of the terror that she had experienced when she witnessed her daughter's accident. Her fear that she might lose her daughter remained very strong and it is not surprising that she felt very protective. It is possible that the ward may have received Sharon from intensive care while she still needed the close surveillance that is available in an intensive care unit and so her mother might have felt under particular pressure to watch over her. To Sharon's mother it seemed clear that she was depended on to watch over Sharon. She described how a nurse indicated to her that nurses were not available for this task when she asked for help:

> Mother: And I used to say to them, "I'm just going to the toilet, can you keep an eye on her?" every time I went to the toilet I told them. And they said to me, the nurses, "You're better off telling one of the ladies that's opposite...
> Int. 24:17

Although Sharon's circumstances were unusual, it was not unusual for mothers to feel responsible for the surveillance of their children and to believe that nurses were not available to substitute for them:

> Mother: Yes, I think, yes if I couldn't stop I would be absolutely worried that she weren't getting, I mean I can give her 24 hour a day care, I think, erm, would she get that with nurses, I didn't think she would, well they can't they can't be sitting at the side all, sleep, you know. I would be worried.
> Int. 30:17

Mothers who were leaving the ward would ask other mothers to watch over their children. A nurse suggested that mothers played an important part in the observation of other children as well as their own:

> Nurse: when we're busy and obviously there's not, perhaps not a person in the bay all the time, one of the parents'll perhaps come out and say to you, "Oh, this baby's vomiting" or whatever, erm, you know, sort of things like that, or "This child wants..", because we don't have, like on the adult side, the kids, er, the adults have a button to press when they want a nurse, because we don't have, have that here. Erm, you know, parents might come out and say "Oh, this child wants a nurse" or something. Erm, which

> makes you feel a bit, not inadequate at times, but because you weren't there, you feel you should have been.
> Int. 35:10

Thus, children's problems could be reported to nurses by the mothers of other children. When nurses discussed their dependence on mothers it was with some embarrassment. The quotation illustrates both the important contribution of parents to detecting problems, whether of their own children or of others and also the sensitivity with which this contribution was regarded by nurses who were concerned about how this reflected on their own care of children.

Disagreement about the level of surveillance required: Frederick

Frederick was a thirteen year old with a learning disability who had spent weeks on the study ward before he was re-admitted during the study. Two nurses told me in some detail the history of the previous admission before Frederick arrived on the ward because they thought I would be interested in the case of the family. Apparently, the relationship between the family and nurses had been a difficult one during the previous admission partly because the nurses felt that Frederick's mother treated him in an excessively infantile fashion. The family also described their experiences during this earlier admission:

> Father: if there was only one criticism of t'hospital, that would be it, I don't think they cater for mentally handicapped children. I don't think it's so much, maybe they don't cater, maybe it's t'wrong word. They haven't got the staff so Ann [child's mother] more or less stopped all the time. I'm not saying she wouldn't have done in any case, but er, he needs twenty four hour supervision really
> Int. 25:3

Frederick's mother was concerned about leaving him and so she attempted to ensure that he would be noticed if he became restless by spreading objects around so that he would make a noise when he knocked them off his bed:

> Mother: I purposely left things on his bed, if he woke up he would throw them off, you know to make a noise to alert anybody. And a couple of times I did come back and everything was all over, he'd stripped his bed, he'd stripped everything, and erm, he'd pulled, er, one of his drips out. And it made me just feel, you know, I just couldn't leave him, but yet I had to go away, you know, I couldn't stop there the full twenty four hours, it's just impossible really. But in the day-time when there were students on, in particular, if they'd got plenty of staff, not so many patients in, it was quite easy to say, you know, "Could someone watch him for me?"
> Int. 25:4

It is interesting that this mother's view about the need of her child for supervision was not accepted by the nurses: the "special knowledge" of the child which was attributed to parents by nurses did not carry sufficient weight for the nurses to provide the surveillance that the mother felt was appropriate. The mother filled what she saw as a gap in the care. The family's experience on Mothering Sunday illustrated to them that the level of care that they demanded would not be provided by the nurses:

> Father: but I think it's all down to short of staff, but Mother's Day, she was in Mother's Day, and she rang me up and said "Come early, bring Alice, and we'll all go and have our dinner together". It were roast beef, wasn't it? So it was a decent dinner, and I think it was the first time we ever planned on having dinner.
>
> Mother: Me mum didn't come that day for some reason. He came in with all these flowers and things, it were right nice, and then we went and asked the nurses if..
>
> Father: We couldn't be spared. She couldn't be spared.
> Int. 25:23

One explanation for the refusal of the nurses to supervise this child could have been that there were insufficient nurses as the family suggested. An alternative explanation could be that the nurses were only prepared to offer the level of supervision of the child that they believed was necessary and that this was not sufficient in the view of the family. Either way the result was that the family celebration was abandoned. Frederick's case was, like Sharon's, atypical. However, concerns about the numbers of nurses available to supervise children and about what the minimum level of surveillance should be were not unusual.

Post-operative observation of the child in a side-room

The study ward had four individual rooms, two side-wards and two cubicles. Staying with a child in an individual room rather than the open ward could be a lonely experience and the isolation of mothers in these rooms was most acute when they were watching over their children after surgery. The fear of leaving the child unattended was very real for some mothers and could extend to fear of sleeping:

> Mother: And she sort of smiled at me from behind t'oxygen mask, you know, as if to say "I'm all right" so I did feel a bit better. And I said to her "I'm going to bed now Angie" I says "But if you want me, just shout" and what did me then was she just sort of pulled the mask away and said "Will you here me with this?" and I thought "Will I hear her with that?" and that were it, I couldn't go to sleep then, I got into bed and I like laid listening for her.
> Int. 47:10

Peter's mother was in a side-room with him when he returned from theatre where he had had a repair of his hypospadias. She felt that she was expected to take care of her child with no concession to her own circumstances:

> Mother: I got the impression, especially based on that night that I asked for Setlers when my stomach was poorly, that like, you know, it's like, what's that expression, I can't think of it now... erm that expression that goes, "Something something, move or get out of the way" kind of thing. That's what I felt like. It was like, either do something or get out of the way, you know [...] they never discussed what I would do, I think they just took it for granted that I was there I would see to all his needs and they would come in and do what their job was, to take his temperature and that sort of thing.
> Int. 46:11

The need for parents to supervise their own children was acknowledged by some nurses, one of whom was strikingly frank in her explanation of how hard-pressed she believed the nurses were to ensure minimal surveillance:

> Nurse: Sometimes, post-operatively you are so short-staffed and you can be so busy, you don't even have time to do post-operative obs. You can pop your head round the corner, just look at the child, and see his colour is still OK, see his chest going up and down so he's still breathing. But you might get one set done and recorded and you mightn't get another set recorded for another hour or two.
> Int. 27:21-2

Comparisons with other wards and hospitals

Those parents who volunteered accounts of their experiences in different wards of either the study hospital or other hospitals seemed to suggest that the study ward was better staffed than other environments. It is necessary to recognise that these comparisons were often made in order to praise the quality of service received in comparison with other wards but nonetheless this does suggest that this ward was not uniquely dependent on the work of parents. First a comment about another ward in the study hospital:

> Father: I wouldn't have liked to leave him any length of time there, because the cubicles also drowned the sound a bit coming out and they didn't seem to be exactly Speedy Gonzales did they Marion? They didn't seem to..
>
> Mother: No, on one or two occasions when I did leave him, obviously you think, they're all right, see to him when he needs it, I came back and he was screaming his head off. They didn't see hide nor hair of him did they?
> Int. 20:5

The comments of parents who had stayed in local hospitals suggested the reliance on parents in those environments:

> Mother: Because when Luke was in with his febrile convulsion they were rushed off their feet. They were, you know, they wouldn't have had time to come and see to Luke
> Int. 26:14-5

One family made a direct comparison between their local hospital and the study hospital:

> Mother: at Studytown it's like, say like two of three nurses to one bay, so if you want anything there's always a nurse there, but at Fartown District General you're traipsing up and down, looking for a nurse, and it's ridiculous.
> Int. 28:6

These comments could easily be over-interpreted and should be seen for what they are, the comments of individuals who are making a point of comparison on the basis of very personal experience. However, they do suggest that parents' belief that mothers made an essential contribution to care did not result from uniquely bad staffing levels on the study ward.

A problematic division of labour

The involvement of mothers in the emotional care of their children is an un-surprising finding and one that will be welcomed by those who have campaigned for the humanisation of children's wards through the involvement of mothers in care. However, problems do emerge in the way in which the work of caring for children on the study ward was distributed between mothers and nurses. Some mothers believed that they were inappropriately relied on to ensure that their children were adequately cared for and there is evidence that nurses agreed with them. It appears that mothers and nurses believe that mothers have become an essential part of the workforce on the ward. Whilst mothers welcomed the opportunity to be involved in the care of their children, everyday maternal care could become stressful following surgery. The naturalistic assumptions which underpinned the division of work between nurses and mothers could become the cause of contradictory and stressful feelings when the child's needs changed post-operatively.

CHAPTER 5: MOTHERS' AND PROFESSIONALS' KNOWLEDGE:

CO-OPERATION AND CONFLICT

Introduction

Mothers discussed their experiences of consulting health professionals as they told the story of their children's illnesses and hospitalisation. It became apparent that some mothers experienced great difficulty in convincing health professionals that their children needed treatment at all stages in the referral process from the community, through other hospitals to the study ward. This was not a topic that was included in the initial interviews but one that emerged from the initial analysis of interview data. The topic was raised in future interviews and proved to be a matter of serious concern to some mothers.

Mothers who stay in hospital to care for their children alongside other health care workers share characteristics of "informal carers", a term more usually applied to carers in the community, often caring for the frail elderly or the long term sick. The distinction between formal and informal carers is useful in understanding some of the experiences of the mothers who stayed with their children on the study ward. "Formal" carers have undergone a professional training and are regulated by a different system of rewards and punishments to "informal" carers (Stacey, 1988). Formal care "rests on a formal knowledge base, in which professionals are trained, and acquire particular technical skills.

The informal sector by contrast is particularistic, marked by strong affect, frequently characterised by effectively inalienable relationships, and by ascriptive status judgements" and the essential differences between the two systems mean that they do not "mesh easily or happily together" (Twigg, 1989). In this chapter the problems that resulted for mothers and professionals from the differences between the knowledge bases of "informal" and "formal" carers are described. Problems arose from differences in the knowledge bases of mothers and professionals. These problems included disagreements about children's health, usually with mothers concerned that they could not convince health professionals that their children needed treatment. In one extreme case it appeared that a child was exposed to serious risk because of delays in recognition of the severity of a problem and referral to the study ward from a local hospital for treatment.

In this chapter reference is made to a range of studies of parents' and professionals' assessments of children and relations between health professionals and people seeking help from them. The data is considered in the context of these studies, which are first briefly discussed.

Professional respect for maternal knowledge

The staff on the study ward acknowledged the expertise of mothers concerning their children. Nurses frequently commented on the special knowledge that mothers have of their children in the interviews and of how the mother's knowledge was essential in order to provide individualised care for children:

> Nurse: they do, they know the child, I mean nobody knows the child the way a mother does, or a long-term carer they know the child so they usually are the best ones for dealing with their care.
> Int. 18:3

There is also recognition in the professional literature that parents have particular expertise in the assessment of their own children, as this statement by a consultant in a paediatric text-book indicates: "The ability to judge what is normal or abnormal for their own child is a skill which parents alone possess" (Spencer, 1984:103). A senior nurse suggested that the special knowledge of mothers was respected by medical staff:

> Nurse: And I've heard a lot of the doctors, certainly here, say "Well we'll ask mum, mum knows best" or I've heard them tell junior doctors "Always ask the parents, it's their child, they know" and it's so true, it is.
> Int. 15:2

Mothers themselves described how they were consulted about their children:

> Mother: I did feel as though the nurses sort of, erm, respected my, erm, if I thought that Patricia was in pain or if I thought she needed something, erm, I did feel as though, erm, they respected my view and they respected what I thought.
> Int. 45:36

Maternal judgement was particularly useful when a comparison with the norm for a particular child was useful:

> Mother: And er they just like said "What do you think to him", because I think they was very worried because he was very pale. And I says "Well he is pale normally".
> Int. 25:8

A study of parents who were invited to a recovery room to meet their children as they recovered from anaesthesia reported a similar reassurance of a professional by a parent:

"one parent was able to reassure a recovery nurse, telling her that 'the bleeding was much worse last time'." (Hall, Payne, Stack et al. 1995).

It was clear that mothers' views were taken into account by health professionals on the study ward but this chapter is concerned with cases where mothers discussed problems which were of importance to the mothers themselves and are also important because they indicate tensions inherent in the meeting of maternal and professional knowledge. The cases which mothers found problematic concerned both relations with General Practitioners and hospital staff and were experienced both by the mothers of children with chronic problems and the mothers of children with acute illnesses.

Studies of the practitioner-client relationship

The relationship between professional practitioner and client has interested sociologists for some time and a substantial literature has developed since Freidson (1960) suggested that the consultation could be seen as a struggle for control. In particular empirical studies of discourse in paediatric out-patient clinics have identified the "ceremonial order" of the consultation (Strong, 1979) and the ways in which discourse can be coercive (Silverman, 1987). These two studies used direct observation and tape-recording of consultations of paediatric out-patient clinics and the present study differed both in the context and method of data collection. Tapes of consultations provide a record of a consultation whilst conversational interviews give a retrospective account from one participant's perspective. The contextual difference is important because the planned encounter of the outpatient clinic is more likely to follow a well established ceremonial order than for example a telephone conversation in the middle of the night when a mother is frightened and believes that her child needs emergency care. In such circumstances social niceties are more likely to be disregarded. However, the question of "differential competence" is central to both contexts (Hughes, 1982).

Influences on maternal decisions about whether a child is ill or not have been examined in the context of mothers identifying mundane illnesses in their otherwise well children (Cunningham-Burley, 1990) and of mothers distinguishing serious from trivial illness in their children (Spencer, 1984). The mother's role as the person who first identifies illness in the child and seeks professional advice is therefore established as important. It appears that many symptoms are treated by mothers themselves and that reference to professionals is only made when the symptoms have been identified as serious, despite some doctors' complaints about inappropriate use of services. The evidence of these studies is that mothers can identify severe illness in children (Spencer, 1984) and that their assessment of their children is based on an intimate knowledge of the child and their normal patterns of behaviour (Cunningham-Burley, 1990).

Differential competence and the normal pattern of consultation

One of the most important differences between a professional practitioner and a lay consulter is the greater competence of the professional: this difference of competence can be viewed as a defining characteristic of the professional in such encounters. The consultation has a "ceremonial order" in which the division of competence is emphasised

(Strong, 1979) and the professional decides which are the important facts and gives the final judgement, in doing so the professional would choose between a number of options including whether to treat a condition or to refer to another practitioner. The encounter is characterised by the practitioner's undisputed right to decide what facts are important and how those facts should be interpreted. Thus, a typical example would be a mother consulting her General Practitioner (GP) about a symptom in her child which caused her concern:

> Mother: she had a very high temperature, very feverish, but she did have a very bad cold. (I: Right) And erm I took her to my GP and he had a look at her and he said "Well I think it's just a bad cold" and we had the general things that they give for colds, erm, but I did mention to him that sometimes, that when she was on the toilet she did cry and said that when she passed water it, it hurt. So we took a water sample in and" (I: Right) erm, the couple of days later when it had been tested, he said "Well, she has got blood in her urine and there is definitely some infection there." So we had antibiotics and that settled it down but within another couple of weeks it had just flared up again. (I: Yes). Erm, so we had different antibiotics this time and he said "Well, I think because of my problem before [the mother's own history of renal problems] we will refer her to [name of surgeon]"
> Int. 45:1

The General Practitioner treated the child's presenting problems, responded to the mother's comments and investigated for a urinary tract infection (U.T.I.) and then referred the child on to a specialist both because of the girl's U.T.I. and the mother's own history of renal disorder. The history illustrated the value of a GP: the child's minor illnesses were treated and the mother's observations were noted, a judgement was made about the response of the child to treatment in the light of the GP's knowledge of the family and then the GP acting as the gate-keeper to the specialist professional referred the child for further investigation and, as it transpired, surgery.

Not all children arrived at the ward through this ideal pathway and problems were experienced by some mothers both in referral and during hospital care which indicate the difficulty of matching maternal and professional knowledge. Cases where there were problems will now be discussed in more detail although it is acknowledged that these examples do not represent the experience of all mothers. The importance of these cases is that they illustrate the problems that can be experienced and the origins of these problems, they are not necessarily representative of the experience of all mothers.

First a case in which a child followed the ideal pathway to the ward is described in detail to illustrate features of the ideal pathway and then cases in which the pattern of the encounter was more problematic will be considered.

The pathway to the hospital

The idealised pathway to hospitalisation of a child is for the child to present recognisable signs and symptoms and then to pass through what have been described as the lay and professional referral systems (Freidson, 1960) until the child is admitted to hospital, treated and returned through these systems to home. One child's journey illustrated this ideal pathway to the hospital but this was not typical of all the children in the study. A closer examination of this family's story helps to identify some points at which the ideal model failed to work for other families.

Recognition of a physical abnormality and passage through the lay referral system

The mother's account started with a routine bath-time when she noticed a physical change in Mark:

> Mother: it was on a Sunday [...] well, while he was in the bath and whilst I was drying him, I thought I spotted a lump on his shoulder,
> Int. 26:1

The mother then discussed her observation with her husband and decided to seek advice from her health visitor when she took her toddler to be weighed:

> Mother: asked you [to husband] to look at it, and you weren't sure were you whether it was one, so I just said, "Well, not to worry, because it's baby clinic on a Monday", I said "I'll take Jeremy to be weighed and ask the health visitor to look at Mark, 'cos I thought it wasn't, I thought I wouldn't go straight to the doctor about it.
> Int. 26:1

The parents were unable to decide between themselves about either the existence or the significance of the lump and so were not confident that it was appropriate to take Mark to his GP. The baby clinic provided an opportunity to seek confirmation from the health visitor before deciding whether or not to see the GP. In this case the parents were using the health visitor as a well informed person who could advise them about the need for the child to be taken to a doctor. The reference to the baby clinic indicated that the mother felt that she needed a legitimate excuse to see the health visitor in order to bring up the subject of her concern about Mark. It has been suggested that the lay referral process is shorter in children than in adults and that there is a moral obligation to ensure that a child is professionally examined which results in truncation of the lay referral system where a child is the patient (Calnan, 1987:151). This may be partly because adults feel less inhibited when acting on behalf of the child than on their own behalf.

The professional referral system

The health visitor advised the mother to take Mark to the GP and made an appointment for the next day. The GP was concerned by a lump that she could not identify and referred Mark on to a local hospital. At each stage of professional opinion the mother's concern was heightened by how seriously the problem was taken and by the speed with which referral was made:

> Mother: she said erm, "No, this is a lump, I don't know what it is, I'll, erm, make an appointment for you to see, better go to the hospital about it". So I casually said, "When do you think that might be?" so she said "Either this afternoon or tomorrow". Well, by that time I was really nervous, my heart was starting to skip beats
> Int. 26:1

An appointment was made for 9:30 am next morning at the local district general hospital, where the consultant was concerned enough to refer Mark on to the study ward, sixty miles away. By Thursday following the Sunday that the lump was first noticed, Mark was in the study ward.

An ideal pathway

The story of Mark's passage through the lay and professional referral systems is interesting because it so closely matches an ideal model: the parents made an observation of a physical change in their child but did not know how to assess the accuracy or significance of their own observations and sought professional assessment. The parents were then passive, once they had taken the child for professional assessment, the professionals made all the decisions about referral on, watched by the increasingly worried parents, who judged the significance of their child's problem by the seriousness attached to it by the professionals.

The referral of other children was less straightforward. In some cases there was not a discrete physical sign such as the lump observed by Mark's parents and parental observations of changes in the child's behaviour pattern made a substantial contribution to the decision to seek professional advice. There were tensions between some parents and professionals, with some parents finding great difficulty in passing beyond the GP, the gate-keeper of the professional referral system. Parents could also find tensions of professional etiquette and ceremonial order which complicated the pathway to the study ward. Some parents experienced very serious problems in progressing through the referral systems and were concerned that their children could have suffered serious consequences as a result. These accounts are more than atrocity stories which are told in order to represent the parents as morally competent to the interviewer (Baruch, 1982): the stories told by the parents are plausible and it appears that justified concerns were expressed by mothers.

How mothers identified a need for health care

The first stage in the process of referral is the identification of a need for health care by the parents. When mothers described how they knew that something was wrong with their child they often referred to behaviours which departed from the child's normal patterns and so the child's behaviour was an important contributor to their concern. This is consistent with evidence of how mothers observe for signs of mundane illness in their children, where mothers are found to assess the package of symptoms and changes of behaviour in a child in the context of their knowledge of the normal for that child (Spencer, 1984; Cunningham-Burley, 1990). There is a methodological problem involved when participants describe how they have decided that their child is in need of medical care, which is that post hoc rationalisation may account for the linking of behavioural observations and children's illnesses (Cunningham-Burley, 1990). The subject is a methodologically difficult one as has been acknowledged (Spencer, 1984). The data must therefore be read with this methodological difficulty in mind.

Changes in children's behaviour which mothers regarded as significant could be very slight. The child might make more demands for contact which would be even less noticeable than the difficulties with eating and sleeping that often concern the mothers of well children (Cunningham-Burley, 1990) and which might be more obvious to an outsider:

> Interviewer: [...] what is it that makes you..?
>
> Mother: Their ways, like, you know. Erm, he'll want, big'un, he'll want to, erm, sit right close to me, and he gets right mardy, you know, whiney mardy, for no reason at all. And that's when I know he's not very well.

> And if he's just got like t'face on, you know, he's quiet, so
> Int. 33:7

The mother said that she could distinguish between occasions where the child was quiet because of normal grumpiness and those which suggested that the child was ill. Such distinctions are subtle and rely on intimate knowledge of the child's behaviour patterns. It is therefore not surprising that the interpretation of the significance of changes in the pattern of the child's behaviour was not always obvious even to other members of the family:

> Mother: I mean, like the night that he [husband] says "Perhaps he wants to come into us bed" and I says "No, there's something wrong", and he says "No, perhaps you're over-reacting a little bit", and I thought "Well, I'll let him have his own way", you know, and he says "No, there's something wrong". You see he's just, I mean he only ever sees him at weekends anyway, 'cos he has to work away.
> Int. 31:23

It is the close daily contact with a child which enables slight variations in behaviour to be noticed and interpreted. The greater contact between mothers and their children presumably explained why it was that mothers noticed such changes and were expert interpreters of their children.

Interpretation within the context of child's normal pattern of behaviour

Behavioural signs were specific to the particular child and were interpreted by mothers in the context of the normal for the child, as Cunningham-Burley found in her study of mundane illness in well children. The child's characteristics as a person were also taken into account in the interpretation of behaviour. During a discussion about the assessment of post-operative pain one couple explained how their child's responses in hospital to a pain scale that used a series of faces from happy to sad failed to measure the child's pain accurately:

> Father: I mean he's laying there in pain, and he keeps wincing and then "Oh yes, that's me, you know, happy" (laughs) and you can tell he's not.
>
> Mother: Well, he's like that, he's that sort of a child, he's a fighter really, you know.
>
> Father: He's very independent, very self-willed.
> Int. 36:21

The behaviour and symptoms of the child were judged against the personality and normal patterns exhibited by the child. The concerns that would lead a mother to seek medical advice were therefore specific to her assessment of what was normal for her own child. The difference between taking a physical sign that would be abnormal in any child and a behavioural sign that might well not be abnormal in other children is that in the first case the judgement is how far the deviation is from the normal for the particular child and in the second the judgement is how far the deviation is from the normal for the population. This different criterion for assessment of what is normal could result in difficulty for mothers, who found that they could only cite their own knowledge of the child as evidence of a problem. For example the mother of Daniel, who spent weeks in hospital following the reversal of a colostomy:

> Mother: And I found that with other parents as well, that they, they you know had real difficulty getting through to some of them that there was something wrong, or something wasn't right.
>
> Interviewer: So, what, is that 'cos you like get a feeling that's difficult to explain, or what?

> Mother: I don't know, you know, I think because they don't know the child as well as you do, they probably can't see it,
> Int. 31:6

Making an offer to which the professional could respond

Because the perspective of mothers and doctors differed it was necessary for mothers to adopt a voice that would be acceptable to the professional (Silverman, 1987:196). Physical signs could be a more acceptable subject for discourse than maternal intuition. This mother found it useful to offer the professional a physical sign in order to ensure a response to her concern:

> Mother: Basically, Frederick has been, he was poorly for about three years, kept taking him to the doctor's, and he said they couldn't find anything wrong [...] so one day he had some black stools so went back down to the doctor's and told the doctor, GP, and he sent him straight down to the hospital and he was in for four days
> Int. 25:1

Frederick's mother felt that she would only get a response if her offer was consistent with the medical perspective. As Waitzkin (1989) suggested "Parts of patients' stories that do not fit neatly into [diagnostic] categories function as unwanted strangers in medical discourse and tend to be shown the door." The difficulty with interpreting the mother's comments is that there is no way of knowing whether her suspicions were vindicated by the appearance of black stools or whether this was a co-incidental event. In addition it is not possible to judge whether earlier investigation would have been fruitful. What was clear was that Frederick's mother found it best to adopt a cautious policy of waiting for physical signs to justify her concerns.

Mothers found that professionals in hospital as well as in the community needed physical signs in order to respond to their concerns. The mother of a child who had a chronic condition took advantage of a liberal admissions policy which allowed her to take the child straight to the hospital without consulting her GP but she still found it difficult to convince the professionals that her child was not well:

> Interviewer: You were saying that when you say there's something wrong then they can't see it, 'cos they're not the, they don't know them?
>
> Mother: No, because it's not something like physical like they've got a temperature. I mean I was like saying "Look, he's lethargic and he won't do anything", and that's one of the first signs with them [episodes of illness], he just loses energy really quickly.
> Int. 31:6

The mother's intuitive knowledge of her own child's normal patterns of behaviour and sensitivity to changes in these patterns may be highly developed but may only get a response from the professional when the signs are recognisable to the practitioner.

The risk of consulting

The changes in behaviour which concerned mothers did not always lead to consultation with a professional. This was not because mothers considered the behavioural change to be insignificant. Frederick had a learning difficulty and his mother reflected on her current concerns during the interview and identified a set of behaviours that caused her concern but which she had not discussed with a health professional:

> Mother: ... in my mind I think he's got something, I don't know what it could be, I haven't got a clue, but he has these times where he just sits licking his hands and that, rubbing his head, and to me it's just not right. And when he goes into, er, Social Services care, you know the respite care, they say he doesn't seem right sometimes to them.
> Int. 25:3

The existence of behaviour that caused the mother concern and a suspicion by the mother that the behaviour indicated an underlying problem were not sufficient conditions for this mother to seek a medical opinion. The mother could not confidently assess the significance of her observations of the child, bearing in mind the possibility that a behaviour change will lead to nothing (Cunningham-Burley, 1990). In addition Frederick's mother could not assess how a doctor might respond to the particular offer of the child's behaviour change. GPs assess the story of a mother and decide whether to treat the child or the mother as a text-book for General Practitioners suggested: "Often one of his [the GP, sic] chief priorities is to decide who is the patient: attention can be focused on the child, on the person who has defined the child as ill, or on the family unit as a whole" (Freeling and Harris, 1984:108). Frederick's mother was aware of this and did not feel that she had sufficient evidence to risk a consultation with a health professional which might lead to dis-creditation of herself:

> Mother: ... I just feel as if they [health professionals in general, including the GP] think I'm being neurotic...
> Int. 25:2

The mother was therefore reluctant to raise her concerns with professionals for fear of appearing "neurotic". The difficulty for the mother lay in her comment that she did not "know what it could be, I haven't a clue". In order to raise her concern with a professional, she implied, it was necessary to have a clearer idea of how the professional would assess the evidence presented. In such circumstances it would not be surprising to find that mothers sometimes delay consultations until they can offer a physical sign to the professional in addition to their own intuitive suspicions.

Expert mothers and the "ceremonial order" of the consultation

The process of referral was not always straightforward for the mothers of acutely ill children but the mothers of children with chronic problems faced particular difficulties. The expertise which such mothers have developed about their own children results in a particularly difficult meshing of the two systems of formal and informal carers. The expertise of GPs lies to a large extent in the assessment of what is normal and routine and so they are faced with difficulty where the condition is atypical. Daniel's mother who found difficulty in dealings with her GP pointed out the limited experience that generalists can draw on and chose the longest serving member of the practice as an example:

> Mother: I mean in all the time they've been there, I mean even a health visitor she's been, oh a health visitor since she was about twenty three and she must be in her late forties/early fifties, and she's only met one other Hirschprung's baby and that was when she was young and training. So I mean they're not going to know the differences are they?
> Int. 31:4

In addition to the behavioural signs that concerned her the mother also knew where to look for physical signs that indicated a problem. Daniel spent weeks in hospital following the reversal of his colostomy with bowel problems, he was constipated but this presented in attacks of severe pain and he did not respond to the standard treatments. Daniel's mother believed that she could identify both physical and behavioural signs when his bowel was not functioning properly. However, she believed that her offer of physical signs was not responded to by the GP because she had identified them:

> Mother: And I kept saying to them "Look, we're bunged up here, I can feel it here, here and here" [pointing to parts of her abdomen systematically] and he was looking, I mean he didn't want to know because I was telling him. No, and he says "Try and get water in him at least quarter of a bottle every quarter of an hour." I went "He won't even look at it, he'll just shut his mouth and look away", and that had been happening for two days
> Int. 31:4

The mother's behaviour was a breach of the "ceremonial order", in which the mother is expected to present herself as ignorant in order for the doctor to present himself as the expert. Strong (1979:70) described how mothers and professionals were idealised in paediatric out-patient clinics:

> "In regard to their children they [mothers] were authorities of unblemished character and competence, but as regards medicine and their relationship with staff they were granted no such authority...Their idealisation as naturally loving and able was counterposed by an equivalent idealisation of their medical ignorance. However much medical knowledge mothers had, or thought they had, they were almost universally treated as technically incompetent. Correspondingly, whatever the actual knowledge or competence of the staff, in practice they both assumed and were granted the mantle of expert."

The doctor's response to this breach of convention was to treat the mother as the problem rather than the child:

> Mother: and then when I took him back in the morning I said "Look, I 'phoned the hospital" and he says "Oh that's what comes from worrying"
> Int. 31:4

On this occasion the doctor that she spoke to at the hospital did not know her and "didn't want to know". The child was admitted to the ward in the morning after the mother had returned to her GP.

Where the child has a chronic problem the assumptions that underlie the ceremonial order do not hold and can even be reversed. The usual expectation is that the doctor will be the expert and that the mother will either be a "woman on the street" who relies on the ritualistic recipe knowledge of every day life or is a "well informed citizen" who has some understanding but is not an expert (Schutz, 1964). The mother of a child with a chronic problem may well have become expert through contact with a rare condition that the GP may have seen rarely if at all. The distribution of expertise is therefore reversed: the mother is nearer to being the expert and the GP is more akin to a well informed citizen. Not only is the mother caught in a double-bind, where she is expected to identify that the child has a problem but then defer to the professional's judgement once she has asked for an opinion (Bloor and Horobin, 1975) but also the GP is caught in a similar double bind that mirrors the mother's. The GP must acknowledge the mother's expertise, or risk dismissing important information, and then offer an opinion as the expert. If the GP accepts the mother's judgement without question the risk is that control of the consultation by the GP is lost and it is no longer possible to claim that medicine is being practised (Freidson, 1975).

The expertise of mothers was also acknowledged by a senior nurse on the study ward who suggested that even the specialist expertise of the hospital staff did not match that of some mothers:

> Nurse: Well, I think the thing to remember is that those children are coming in with those specialist disorders, like a child with spina bifida and hydrocephalus, the parents have been with that child since it was born and half those parents know about those conditions inside out, they could teach us a thing or two.
> Int. 18:12

By-passing the General Practitioner

It is not uncommon for paediatricians to give mothers permission to bring their children directly to hospital, particularly where the child has a chronic condition. The invitation to by-pass the normal gate-keeping system of the GP is an implicit acceptance that the mother is in a better position to assess when her child is ill than the GP. Where the GP resents such disregard for professional etiquette the mother is in a difficult position which can make the use of primary care difficult or even impossible. If she consults her GP there is the potential danger that sufficient significance will not be attached to the child's problem and that the GP might respond to breaches of ceremony rather than to the child's problem. If she does not use the GP then she is left to rely on the hospital as her first port of call. This can be problematic because of the distance involved which can mean a choice between a telephone conversation and a long drive in order to get a professional opinion.

Telephone contact with the hospital is therefore of great importance to the mothers of children with chronic problems but conflicts of ceremonial order can also arise in such conversations as a result of the expertise of the mother.

The mother of a child with a rare syndrome that includes cardiac malformation reported a telephone conversation with a doctor at her local hospital (not the study ward):

> Mother:..I mean, erm, you know how t'doctors change over every six months at t'hospital, I rang up, and I said er, because she'd been in heart failure a few times, so I knew what I war watching for. And, er, we war at your house [to mother-in law], warn't we when it happened? Were it that time that I rang up and it war t'Scottish doctor that answered. And I said, er, can I fetch her for a check-up, and she says "Oh, why don't you get your doctor out?". I says, "Well, I'm a bit worried about her," I says, "last time she was like this", she says, she you know, "she went into heart failure". "Oh you're a doctor are you, you know what to watch for?" "Well", I says, "she's been in a few times, so..." She says "Get your GP out". I says "Forget about that", I says, expect me in half an hour." She'd gone off duty and a male doctor saw her and he says "I'm sorry, love", he says, "she's in heart failure".
> Int. 29:1

The mother was challenged by the doctor to justify herself as a legitimate diagnostician: "you're a doctor are you?", with the clear assumption that the mother was not a doctor and therefore not in a position to diagnose her child's problem. The doctor sought to restore the normal ceremonial order of the consultation, where the mother presents herself as incompetent and thus co-operates with the doctor in her presentation as an expert. In addition the doctor was concerned that the mother was by-passing the professional referral system. The socialisation of trainee doctors makes such breaches of etiquette a serious matter. The only solution for this particular mother was to take the child to the hospital to be treated, where her judgement was vindicated.

Dealing with specialist professionals

As the gate-keepers of the professional referral system GPs present an obstacle for parents who believe that their child is sick. There are also particular difficulties where generalists deal with rare conditions. However, this is not to suggest that dealing with more specialist staff in hospital is not problematic for parents. The relaxation of the conventions of the professional referral system which paediatricians allow for the mothers of children with chronic conditions is based on the principle that it is better to assume that a child is unwell when it is not than to assume it is well when it is not (Scheff, 1978). However, the difference of perspective of mothers and professionals remains even though the balance of expertise is more conventional than when expert parents deal with generalist GPs. Mothers continue to draw on assessments of their children's behaviour and their own interpretations of the extent to which these depart from the child's own norm. However, specialist professionals, like their generalist colleagues are often dependent on physical signs in order to use medical science to respond to the concerns of mothers.

Behaviour continued to be an important indicator of the child's condition to parents even after a specialist had diagnosed the problem. In this case the parents described how the lack of behavioural signs reassured them even after their child had been diagnosed as having an abnormality of the renal tract:

> Father: Well, it warn't worrying us because it were like, he were on top of it.
>
> Mother: It weren't worrying us because he weren't poorly, if you know what I mean. If he'd have been like, poor-, well, crying all t'time, or as though he were in pain, then it would have worried me then, but as it war, it just didn't worry me.
> Int. 33:2-3

Mothers continued to observe their children's behaviour closely in hospital and to notice patterns of behaviour that developed. However, for acute admissions in particular there was the problem of the influence of hospitalisation on the child's behaviour:

> Father: Well, he was sedated, weren't he, for three or four days, so you can't, the kid's not natural is he? So you can't get their natural reaction.
>
> Mother: No, 'cos you know, when they're injecting him with stuff, you don't, it mixes 'em up a bit, don't it, really, it swings them, so..
> Int. 33:17

For parents whose children's behaviour changed following admission and treatment an added uncertainty was introduced that made the interpretation of the child's behaviour more complicated. Despite this complication, mothers felt that they were in the best position to judge their child's behaviour and some feared that the child's care would suffer if they were not with the child to make such judgements. The mother of Andrew, a two year old who had undergone a hypospadias repair felt that nurses would not be able to understand her child's needs:

> Mother: would they have let it, him sort of, like let him go for a while, you know, in pain, screaming, would they have let him cry and not seen that he was in pain, would they have just thought that he was missing me or something like that? So I must say, like, you know, I would recommend that the mother stay if at all possible with a young child,
> Int. 46:7

The different perspectives of professionals and mothers

The professional-lay encounter can be seen as the scene of a struggle for control in which the professional is usually assumed to have greater competence. Retrospective interviews do not provide evidence about the strategies for control used in the encounters by mothers and professionals. However, conflict between mothers and professionals is not necessarily explained by strategic communication where the mother and professional compete for control. An alternative explanation lies in the difference between the perspectives which underlie maternal and professional knowledge.

Hughes (1982) suggested that even when doctors give patients opportunities to influence the agenda of the discussion, patients are not in a position to judge what is relevant. This argument would suggest that attempts to involve clients in treatment decisions are unlikely to be successful because the client will usually lack the competence to make a contribution to the decision. However, some mothers develop considerable expertise in the identification of illness in their children and so the problem that they face is not that they do not know as much as the professional but rather than their knowledge is of a qualitatively different nature.

Maternal knowledge is knowledge that has developed through intimate contact with the child in the private domain of the home. The mother knows her own child intimately and so is able to make intuitive judgements about when the child is unwell. The mother's judgement is by definition not scientific or objective: it is the closeness of the mother to the child that enables her to become an expert judge of the child. These features of maternal knowledge distinguish it from professional knowledge which arises from the public domain of a working world in which high value is placed on the objective, scientific approach to understanding problems. The distinction between public and private worlds has been identified as important in the understanding of women's experience (Gamarnikow et al, 1983) and the distinction between objectivity and subjectivity is often linked to gender. The differing perspectives of mothers and professionals meet in a social context where the mother has less authority than the professional and in many cases where the female mother presents her concerns to a male doctor. The difference of perspective cannot be seen in a social vacuum but occurs in a context where the mother has less authority than the professional, both because she is a mother and a woman.

Authority of maternal knowledge and "special expertise"

Despite the doubts concerning the scientific admissibility of maternal knowledge, it has authority in the private sphere which can extend into the public. The moral construction of motherhood means that professionals acknowledge the mother as an expert judge of the child in the private domain. Medical diagnosis requires access to the private world and young children cannot provide a reliable account of their private experiences because of their level of development in cognition and communication. Mothers are able to provide the information that is acquired through everyday intimate contact. However, mothers are not only regarded as a useful source of information but also as judges of information. Mothers are asked to make a judgement about how a particular event compares with a normal pattern ("Is he normally like this?") and so mothers are not just witnesses but expert witnesses.

The private nature of maternal expertise both defines and limits its status. The interface between private and public knowledge is a grey area where conflict arises between mothers and professionals as the boundary between public and private knowledge is determined. The accounts of some mothers suggested that this is a large grey area where there is considerable uncertainty about whether the mother's or the professional's knowledge is the most appropriate.

Limits of knowledge arising in the private domain

Medical and nursing staff are faced with a problem when a mother tells them that she knows that her child has a problem that they have not identified. The mother does not have the authority of medical training, and perhaps even if she was a qualified doctor this would be discounted because her position as a mother would undermine the claims to objectivity and detachment required in the public domain. A mother's comment (below) implied two explanations for the response of professionals. Firstly the nature of the knowledge that mothers offered, which was personal and subjective and secondly the lack of status of mothers apropos professionals:

> Mother: Yes, but they don't, I think it's because you're just a parent, that they think that "Oh well, they've got no degree in this", but I know him like the back of my hand, you know. Harry I wouldn't know when he was ill, for the simple reason that he's never been ill.
> Int. 31:5

However, what are the professionals to do with the mother's judgement? The mother must suggest physical signs and/or symptoms that can be recognised in medical discourse, her own assessments of behaviour are not sufficient in themselves. Maternal judgement is valuable in so far as it serves to alert the professionals to problems that can be identified and treated and so maternal judgement can be seen as an auxiliary rather than an alternative form of judgement. The mother's judgement is useful to health professionals when it draws their attention to a recognised set of signs and symptoms that form the pattern of an accepted medical diagnosis which can be treated. When the mother's judgement presents the professionals with a set of signs and symptoms that do not fall into such a pattern a dilemma results for the professionals because they are not able to use the mother's knowledge and a frustrating impasse results for the mother because the professionals seem unable to respond to an obvious problem. Mothers experienced this problem when their children did not follow a text-book pathway because either their illness or their response to treatment was atypical.

The story of a mother whose child was in hospital for some weeks with bowel problems following reversal of a colostomy indicates the frustration that she experienced in trying to convince the professionals that something was wrong with her child and illustrates the conflicts that can arise between private and public understandings of a child's problems.

> Mother: Yes, it was about four weeks, yes, round about four weeks that he actually had a big attack, because they were just concentrating on the actual being bunged up, and I was saying "There's something else going off", you know. He was just screaming after each meal, or he'd be so uncomfortable just like his food had got stuck or something, you know, I was really trying to drill it into them that there was something wrong.
>
> I: Yes.
>
> Mother: That I found hard, and I was quite frustrated because I was thinking "Perhaps it's just me" and you do, you end up thinking like that, mm. And trying not to like bother them unnecessarily, I'd think "Oh if I moan too much they'll think 'We've got a right one here'. And eventually I thought "No, this is ridiculous, I've got to do something".
> Int. 31:7

This mother fought a lonely campaign for her child's problem to be recognised by the professionals. Her comments indicated that she felt that the campaign was also one to establish that she was a competent person and not making a fuss about nothing. The mother who feels that something is wrong with her child but finds that no medical diagnosis can be established is in a particularly vulnerable position because the absence of a medical diagnosis places her at risk of being discredited as a mother:

> Mother: But they could make you feel very little, you know like you really didn't know what you were on about, and, when you were trying to explain you could almost see it in their face like "Oh, we can't see anything wrong", you know. Eventually they did listen, I think they realised I wasn't neurotic after all (laughs), you know.
> Int. 31:14

The comment that eventually the professionals realised that the mother was not neurotic after all, reveals that this mother felt that she had to prove her innocence from this charge, that she at least felt that a presumption of guilt had to be disproved. The case did not only have to be proved to the health professionals. The absence of a medical diagnosis and treatment was a cause for questioning of the mother by her relatives:

> Mother: Yes, you get pressure from family as well. You know, like saying "He's not well", "Oh he's this" and "Oh he's that", and then other days they'll say "Oh he's fine, there's nothing wrong with him," you know, and you say "There is something wrong" you know like, even my mum...
> Int. 31:33-4

The mother who argues on the basis of her belief in her child's problem risks dismissal as an over anxious parent who sees problems where none exist. The step from this state of discredited mother to the suspicion that the mother is suffering from a personality disorder such as Munchausen's Syndrome By Proxy is perhaps not that great. The mother is open to suspicion and may be completely isolated with even her family suspecting her judgement.

The story of how this particular mother was able to finally convince the professionals that something was wrong illustrated the hierarchical way in which credibility is attached to observations.

> Mother: I just had to wait until he did something to prove to them, you know, or I called them when he was doing something or other, so I mean there was, when I first went in he kept getting this great big lump in his side, but it'd come and go so quickly, so by the time I had shouted someone it had gone. So I mean, there was a student there and it actually happened whilst she was there and she went "Oh, God, yes" and I mean it comes to about the size of an egg, and then disappeared again. And this one nurse said ... "Did anyone else see it?" and I says "Yes, this student", and they never went and asked that student...
>
> I: So it was only when the Sister saw it that it got believed?
>
> Mother: Yes, the actual Sister.
> Int. 31:8-9

Who knows best? The problem of identifying pain in children

The extent of the grey area where it is not clear whether maternal or professional knowledge is most appropriate to understanding a child's problems is illustrated by the case of pain in children. It was clear from the accounts of nurses that they were uncertain about whether their own professional knowledge or mothers' personal knowledge was the best guide to deciding whether a child was in pain.

The boundaries of the public and private domains are not clearly defined when a child is hospitalised. Three types of uncertainty inherent in health care decisions have been identified by Fox (1979). There is the uncertainty of whether the practitioner knows what there is to be known, there is the uncertainty arising from the limitations of science and the uncertainty about which type of uncertainty applies in a given situation. Where children are hospitalised there is an additional form of uncertainty about whether a given problem is best understood in terms of knowledge from the public or the private domains. The difficult question of how to assess pain created particular problems for mothers and nurses, each being unsure of the extent to which their own or each other's expertise was most appropriate. The mother of a two year old child who had elective renal tract surgery was asked by the nurses for her own opinion about whether her child was in pain or not when the child started to have "paddies" in which she would cry "hysterically". Her account illustrated the uncertainty experienced by both nurses and mothers:

> Interviewer: Did you feel that you, you knew whether she was in pain or not, or did it sort of worry you when they [the nurses] asked you?
>
> Mother: The first, the first time that she actually did it, it worried me because I wasn't sure myself. I gave the nurse a reply, "I don't know, I really don't know" I said "She doesn't usually do this" and then I said to the nurse "Do you find that children do have fits like this?" 'cos I felt that she would probably know more, erm, she would know if children did this sort of thing, I felt as though it was probably the sort of pattern of how things went. And she said to me "Yes well they, they can get like this" erm, and I explained that she didn't usually do it. And then obviously when she had it again and again, she had three or four do's like this and she'd end up crying herself to sleep, er I did feel as though it was just the frustration. I felt easier the second time, but the first time I just didn't know I said "I don't know". And nobody I think could have re-, even when the nurse said "Well they do do things like this" that didn't really reassure me, make me think that, I was still wavering, wondering whether it was pain and that there was anything wrong.
> Int. 45:24

The child's behaviour was not easily explained by either the mother or the nurse. The mother felt that the behaviour was not typical of her child but she could not explain it in terms of her knowledge from the private domain because the child was in an atypical situation, in hospital following surgery. She hoped that the behaviour would appear typical to the nurse, that it could be explained by expertise in the public domain. However, the nurse's statement that "Well they do do things like this" did not convince that mother that her child's behaviour had been explained. The uncertainty about how seriously to judge the behaviour remained.

Nurses also reported difficulty in judging whether children were in pain and sought insights form the private domain of the mother's knowledge of her child. A nurse summed up the meeting of the public and private domains in the assessment of pain:

> Nurse:...Pain is a difficult thing to deal with I think with children and parents...you've got to be able to advise what, what type of painkillers you feel are appropriate, but you've also got to be able to listen to the parents, 'cos they know their child, they've looked after their child for five, six years, so they know when their child has got pain. Erm, but then you also know the sort of pain that is expected of a particular post-op patient, and should be able to assess to a certain degree of what type of pain the child should be expected to be in.
> Int. 40:22

Studies of pain in hospitalised children have not produced clear cut evidence on how effectively parents judge their children's pain (Gillies, 1993) and so the uncertainty about whose knowledge is most appropriate remains.

The dangers of ignoring the mother's concern: the case of Lawrence

The case of one child who was treated at his local hospital before being transferred to the study ward illustrates the dangers of professionals ignoring the mother's concerns. Lawrence was a three year old who was under the care of a paediatrician for speech and eating problems. Lawrence spent a few days in his local hospital and was discharged on a Friday. He had a severe haematemesis on the Sunday morning and was re-admitted to the same local hospital. His condition did not improve and he was transferred to the study ward on the Sunday evening. He underwent an emergency laparotomy and appendectomy immediately he arrived and he was transferred to intensive care following the operation where he required a blood transfusion and intravenous feeding. His mother asked the surgeon what would have happened if he had not been transferred from his local hospital:

> Mother: I said to the surgeon, I said what would have happened if Lawrence wouldn't have got here tonight, when he did. And [the surgeon] said "Well, I wouldn't have been doing t'operation" (I: Mmm) in other words that he would have died.
> Int. 48:6

The mother felt that her concerns had been ignored at the local hospital:

> Mother: I felt as if everyone thought there were nothing wrong with him and it were me, you know, like, it were me making out there were something wrong with him and there weren't nothing. It's like everybody on that ward, I know, I know for a fact, they all thought, there's nowt wrong with him, he's putting it on, and I'm just flapping for nowt.
> Int. 48:15

The child was discharged from the local hospital on Friday despite the mother's concern that all was not well. The mother said that Lawrence was eating a crisp when the doctor saw him:

> Mother: I were worried because he hadn't eaten anything for all this time, and er, I got some crisps, so I give him one crisp and it were like took him hours to eat it, and as he was eating the crisp, the doctor walked into the r', into t'room. And he said "Oh, Lawrence is better now, look he's eating a crisp" I said "Oh, it's only one that he's had like off er me". I said "He won't eat nothing else". Anyway he said "Oh he's all right, he can go home".
> Int. 48:2

She had been told that Lawrence had stomach pain as an after effect of gastro-enteritis. She judged Lawrence against his normal pattern of behaviour:

> Mother: all day Saturday he were like very, very quiet, he wasn't his usual self but he's not one for moaning and crying, if there's anything wrong with him, he never has been [...] So I knew there was definitely something seriously wrong with him.
> Int. 48:2

Lawrence was re-admitted on Sunday after his sister had found him in a pool of altered blood that he had vomited. The mother described the paediatrician attempting to ask Lawrence about his symptoms:

> Mother: Now Lawrence is under him as well because he can't talk properly, he's had speech therapy, and he's asking Lawrence if he's had anything to eat, which I were just gobsmacked, because he knows Lawrence cannot understand and cannot talk properly. And I kept saying, you know "Well, Lawrence dun't know when he went.." he were asking Lawrence if he'd been to the toilet and if he had a pooh and if it were hard or soft.
> Int. 48:3-4

The sight that this account conjures up is an odd one: the doctor asking a child who is known to have speech difficulties to give a history, while his mother watches. -It would seem from this account that there was a lack of trust in the mother as a witness to the child's behaviour. Lawrence stayed in the local hospital for some hours and it was when a member of staff encouraged her that his mother insisted on referral to a paediatric surgeon. Once Lawrence arrived at the study ward the surgeon recognised that he was very ill:

> Mother: [the surgeon] never even touched his stomach because [the surgeon] could see he were in that much pain. [The surgeon] never even touched it, just said to me "I'll take him down, I'll open him up, I might find something, I might not, but that's like the chance you have to take."
> Int. 48:4

By the time Lawrence had arrived on the study ward he was obviously a very sick child who needed emergency surgery urgently. The local hospital did not appear to have realised the gravity of the child's condition and it appears that the mother's concerns were dismissed. It is possible that this mother was retrospectively rationalising a distressing series of events and attempting to present herself as a morally competent mother who was ignored by the professionals, in short that she was telling an "atrocity story" (Baruch, 1982). Retrospective interviews can only be read with such a possibility in mind. However, the mother's story is a plausible account which is detailed and told in a credible manner. The fact that a child needed intensive care, parenteral nutrition, and blood transfusion following an appendectomy having spent the previous week in hospital suggests that something went wrong with the early detection of a treatable condition. A post-script to Lawrence's story is that his mother went into premature labour and delivered a baby that died within an hour during his hospital stay. It is not possible to say whether this event was linked to the stress that the mother experienced during his illness but it is possible that the health of the mother as well as of Lawrence was affected by the slowness with which he received treatment.

Implications for practice

The expertise of mothers about their own children can be seen as a resource which professionals can draw on when caring for children and this view was reflected both in the comments of nurses in the study and is to be found in medical text-books. It is usually assumed in discussions of maternal knowledge and of the differential competence between professionals and lay clients that differences between professionals and mothers are differences of the quantity rather than of the nature of knowledge. Stacey (1988:210-1) suggested that mothers' knowledge of their children's illness was inherently similar to that of health professionals:

> "women all too often find that our knowledge and understanding is devalued. Obviously lay women do not have the technical language but know and understand more than many professionals imagine... The mother's knowledge is in a different form but it is about the same thing as the doctor is concerned with. The tragedy is the professional's 'trained incapacity' (Merton, 1957:197-8) to hear what is being said."

However, the knowledge of mothers is not about the "same thing" as the professional is concerned with: the mother's knowledge is of the slight changes from the usual pattern for that particular child while the doctor's concern is predominantly with physical symptoms and deviations from the norm for the population. The difference is fundamental because maternal knowledge arises from sustained contact with the child in the home whereas professional knowledge is the product of the public world of work.

The different knowledge that mothers and professionals brought to understanding the problems of children in the study resulted in conflicts between mothers and professionals. The problem is a complex one which becomes more difficult the more that mothers are involved in the care of their children. Calls for professionals to pay attention to what mothers say are therefore of limited value. The professional is only in a position to respond to information which can be understood within the professional perspective. It would be foolish to suggest that mothers are always right in their judgements about their children.

There would be little point in consulting a professional at all if the mother were always able to make an accurate diagnosis. Professionals who wish to take account of mothers who may be able to offer valuable expertise need to be able to interpret the mother's statements and to place them within the professional perspective. It would be useful for such professionals to know more about how mothers make their judgements about children in order to make the process of interpretation more sensitive and effective.

CHAPTER 6: THE COSTS OF INVOLVEMENT

Introduction

Families' decisions to spend time with their children in hospital involved considerable costs. The costs of staying with children were both financial, through expenditure and loss of income and social, through incurring debts of obligation to kin. These costs were characterised by their unpredictability and as a result the open-ended nature of the commitment that families made. It was clear from the accounts of parents that the burden of cost was much greater for low income families and that little financial assistance was made available to alleviate this burden.

Definitions of "cost"

Modern economists use the concept of "opportunity" to define cost. Rather than measuring the effort and sacrifice that is required in order to acquire a good or service, economists define cost in terms of the opportunities that must be foregone (Greenwald, 1983; Gilpin, 1986; Pearce, 1986). The concept of opportunity cost is particularly appropriate to families of hospitalised children. Families "paid" for their involvement in the care of their children in hospital in a variety of monetary and non-monetary ways, which included lost earning opportunities, cash payment for goods and services that enabled them to be with their children and lost opportunities for privacy, autonomy and independence in family relationships.

The concept of "borrowed time" has been used to explain the costs that women pay as they manage the "practicalities, task scheduling and negotiations" required in order to consult professional health services (Pearson, Dawson, Moore, and Spencer, 1993). It has been suggested that women from low income socio-economic groups prefer to "borrow time" from kin rather than friends or neighbours because kin relationships are more likely to provide the high degree of trust, reliability and flexibility that is required when health services are consulted.

> "By contrast, reliance on favours from non-kin may afford less flexibility and may threaten carefully protected privacy, implying more immediate resource exchange for needs which are less predictable" (Pearson et al, 1993).

The exchange of child care between working women has also been discussed in a study of how working women manage the child care problems that arise during minor childhood illnesses (Hewison and Dowswell, 1994). The families of hospitalised children often have to organise alternative child care when a mother stays with her child in hospital and so borrow time. However, the currency of repayment was not always time, repayment could also be in the form of loss of privacy, autonomy and even the freedom to adopt a stance in a family dispute.

Families paid costs both in order to get to hospital to be with their children and in order to stay in the hospital once there.

Getting to hospital

Mothers who described themselves as housewives could buy their time in hospital through re-organisation of domestic responsibilities, for example by filling the family freezer with prepared meals in advance. However, only thirteen out of twenty four mothers described themselves as full-time house-wives, the remainder were in either part-time or full-time paid employment. These mothers bought the time to be in hospital with losses of income, holidays and potentially also loss of reputation as reliable workers. The costs in lost earnings could be substantial:

> Mother: Well I lost a lot of money, it cost me five weeks. Yes, I were, altogether it's like been five weeks, that I've not been at work.
> Int. 48:11

Fathers were more likely to continue to work during the hospitalisation unless they were required to substitute for mothers. However there were several fathers who had been laid off by their employers and they described their unemployment as a blessing in-disguise because it allowed them to be involved in their child's hospitalisation, although at the cost of lost income.

For some families the cost of time to be in the hospital was the use of a substantial proportion of their annual holiday entitlement:

> Father: Yeah we had to swap us holidays round, didn't we? (Mother: Yes) so that, like she war off t'fortnight and then me, I were basically working, I earn more, so it's better off

> that, she had her holidays and I had mine whenever, and as I say I go through every day, so...
>
> Interviewer: Yes, yes, so I mean, you must have used up a fair bit of holiday then?
>
> Mother: Two weeks holiday it were, and a few odd days.
>
> I: Yes, that must have been most of your year's?
>
> Mother: Yes, I only get three weeks anyway.
> Int. 43:2-3

Some of these costs were incurred after discharge, when children were at home but continued to need the close attention of a parent.

There were also financial costs incurred as a result of travelling to and from hospital. Since this was a sub-regional centre for referral, some families had considerable distances to travel, up to approximately 100 miles, in order to be at the hospital and transport costs could therefore be high.

> Mother: it's expensive for your husband, we spent £25 three days in petrol, erm, so you know, it was just er, well she's got to go in you end up paying that's it, yes it is expensive.
> Int. 30:22

In addition to the financial costs, mothers who had other children could not get to hospital until they had made arrangements for the care of their other children. For some families alternative child-care posed real difficulty, resulting in extremely complicated arrangements for the care of their other children during hospitalisation. The difficulty could arise from lack of local support or from fears about the emotional welfare of their other children. For example, a father described the arrangements made for the brother of a hospitalised child and indicated the importance of ensuring that he did not feel excluded by separation from parents as he had during a previous admission of his brother:

> Father: Well, he stopped with my mother because she's only two streets away, and he felt as though he got his nose pushed out, 'cos it was like a rush, it weren't pre-arranged. So this time we asked who he wanted to stop with, so he stopped with my mother a couple of nights, Eve's mother for a couple of nights. And he also stopped with a friend of ours like who's, who is their daughter's same age as him. So we let him do what he wanted, like, I picked him up at night to go to t'hospital like.
>
> Mother: We asked him if he wanted to come, if he didn't want to come, then.
>
> Father: We didn't pressure him into it, so he felt more relaxed like and then he were excited about seeing him.
> Int. 33:4-5

Kin relations were the most likely to be turned to by families, although friends were also used. Other mothers did not have local family or friends that they felt able to call upon and arranged for their children to stay with members of their families during the hospitalisation. It was not always possible for children to stay near their own home and the result could be children staying with relatives miles away from both their own homes and the hospital. One such mother's account illustrated the reciprocal nature of these exchanges when she explained why she felt that she had to take her children to a sister who lived about ten miles from the hospital:

> Mother: She, erm, my sister that lives in Smalltown, the first time we was going up she said "Don't worry about Nicola, fetch her with you and I'll look after her". My mother was going to look after her, but, there was a big sort of argument erupted in the family.
>
> Father: Well, mother and father-in-law were going through a divorce at the time, you see. It gets very...

> Mother: Mm, my mother and father were getting divorced and there was a big sort of argument erupted in the family and it ended up with me not speaking to my mother, which I still don't.
> Int. 28:18-9

Borrowing time from her own mother would have meant that this mother would have had to pay the unacceptable price of relinquishing her stance in a family dispute. Whilst the opportunity to take a stance in a family dispute was not frequently mentioned, other mothers paid a cost in independence in their relations with kin because of the need to present an acceptable account of their child's hospitalisation in order to borrow time. This was more than a loss of privacy, because the mother's behaviour could become a topic of family scrutiny and discussion. Kin could question the need for the child to be in hospital at all and the moral competence of the mother's decision to stay with the child. Mothers felt that they had to present an account of their child's illness and their own behaviour. If the child's problem was not straightforward and the hospitalisation was extended the demands for explanations could seem particularly intrusive. A mother whose child was treated conservatively for several weeks in hospital with an atypical problem explained how her account to kin was principally designed to prevent further questioning and examination:

> Mother: ...you know they'd [the family] say "What are they doing?" and I, and I've had to say "nothing" because they weren't, they were just watching him, so I'd like say to my mum "Well they can't do too much with him because it'd cock his system up". "Oh, right", and they'd leave me alone, you know. It was the only thing I could come out with just to shut 'em up. "They can't be doing two things to him all the time, it wouldn't be fair", "Oh no, you're right".
>
> Interviewer: So you were fending them off in a sense, yes?
>
> Mother: Yes, "Go away", you know.
> Int. 31:35

Children whose chronic illnesses require them to have frequent contact with health services make extra demands on the resources of their mothers. Clarry had been admitted to hospital on approximately 28 occasions and her mother had borrowed extensively from her mother-in-law who cared for Clarry's brother during these hospitalisations. When I interviewed them it was obvious that the relationship between the two women was tense and it erupted into open hostility on occasions during the conversation. The mother-in-law interrupted in order to contradict Clarry's mother and criticise her behaviour and the way that she discussed her experiences. Clarry's mother took the opportunities of her mother-in-law's frequent absences from the room to describe various disputes that she had with her mother-in-law about the care of the children. When her mother-in-law was out of earshot Clarry's mother explained that there was an ongoing dispute in the family about the attention that she gave to the two children:

> Mother: I mean family's telling me an' all that I'm putting too much towards Clarry and not enough to him [the sick child's brother]. So, which annoys me, [laughs]
> Int. 29:8

The mother-in-law also said that she believed that staying in hospital at night was not always necessary. Given the reliance of Clarry's mother on her for child-care, the statement suggested that Clarry's mother would have to overcome resistance in order to stay in hospital with Clarry. These comments and the way that Clarry's mother and her mother-in-law behaved suggested that there was considerable tension in the relationship and that the mother-in-law was attempting to influence the extent to which Clarry's mother was involved in her hospitalisation. Mothers who have to rely on borrowing time from relatives may have to pay a price in privacy and autonomy. Privacy is under threat because requests of kin for time and other resources must be accompanied by an explanation of the justification for the request. The mother's decisions and behaviour are then potentially the subject of scrutiny by kin who may question the moral competence of the mother's actions. Mothers may fear that their autonomy is at risk because kin may use the need for assistance as a bargaining tool in order to gain influence over decisions about parenting that they would not otherwise be given, either related or unrelated to the hospitalisation.

Staying in hospital

Once the costs of getting to hospital had been incurred, families were faced with further expenses. For example, it was necessary to buy drinks and meals in the hospital canteen where the ambiguity of the role of resident parents was reinforced. Parents neither received free meals as recognised clients of the hospital nor the discount offered to recognised workers.

> Mother: eating there was really sort of expensive, that was one thing we found, it was really expensive to eat there. I mean it was coming to about 4 pounds or 5 pounds for a meal, for something substantial. I mean if you got a packet of sandwiches and a drink. But you had to have one hot meal a day, I mean, something like fish, chips and peas and a drink would come to about 5 pounds between us.
> Int. 28:16

The child's care could also result in direct expenditure. Eating and drinking was regarded as part of maternal care but children could be very reluctant to drink following surgery. The nurses would be concerned that children would become dehydrated and be at greater risk of infection if their liquid intake was not sufficiently high. The parents of a boy who had undergone a hypospadias repair said that he was reluctant to drink and their comments demonstrate the extent to which the need to ensure that the boy had sufficient to drink had been stressed by nurses. The responsibility for ensuring adequate liquid intake remained the mother's despite the special circumstances of post-operative care, when children are often reluctant to drink and where liquid intake is particularly important. These parents described how the need to ensure that their child drank lead them to spend money in a vending machine:

> Mother: ..he had to drink I think it war a glass every hour..I had to be there to make sure he did do...we had to actually try and shove it down his neck to like push all t'badness through.
>
> Father: What we had to do was to spend a fortune on cans of coke.
>
> Mother: 'Cos he loves Coke.[...]
>
> Father: They told us he had to drink all this didn't they?
>
> Mother: Yes, like I said they were checking, checked up every other hour to make sure he were drinking enough.
> Int. 22:12

The pressure to ensure that her child drank enough was felt keenly by this mother. The use of the word "badness" implied a moral duty to purify the child as well as a physiological need for liquid. In these circumstances the need to ensure that her child drank sufficient overrode other considerations. The family believed that some of the difficult behaviour of their child since he came home from hospital resulted from their concern to ensure that he drank following his surgery:

> Father: ... it's been hard to get him back into t'mould we had him in before...What he's been doing, he's been getting a lot of sweets, and fizzy drinks, hasn't he, and apparently it makes 'em hyperactive. So we've cut his sweets out quite a lot and his drinks, only as a treat now. And, 'cos he

> expected it before, he's a bit.
> Int. 22:18

The need to ensure that a child co-operated with treatment could lead to the offer of bribes to children which were a further source of expenditure. In one case the mother said that nurses had bribed her child with money in order to persuade him to have a dressing removed. Apart from any consequences in terms of family dynamics, further demands could be expected and result in additional financial costs.

An open-ended commitment

A feature of the costs to families was their unpredictability and the open-ended nature of the commitment. Some families tried to plan ahead for hospitalisation, saving holiday entitlement in order to avoid loss of income and difficulties at work. This was a process of saving goodwill as well as finance, for example a bus driver sacrificed his Christmas off-duty in order to ensure that he had gained goodwill by working an unpopular shift and that he would have holiday free for when his child was admitted. Cash was also saved in preparation for the admission:

> Mother: But the first time we went in we were prepared to stay so we saved for a while, we took a considerable amount with us, but the second time we went in..
>
> Interviewer: You took some money do you mean?, yes.
>
> Mother: Mm, but the second time we had to go down, I mean we was only expecting to stay for the day, plus we claim Family Credit anyway, so we took the Family Credit book with us, sort of lived on the breadline if you like, sort of made it spread out, because eating there was really sort of expensive, that was one thing we found, it was really expensive to eat there.
> Int. 28:16

Despite planning ahead, this mother's comment illustrated that financial costs were only predictable to a limited extent and so it was not always possible to plan a budget in advance. Costs resulting from travel, loss of work and holiday could be calculated before admission because the distance between home and hospital would be known and parents of children who were to be admitted electively for routine procedures would be given an estimate of the length of admission by the surgeon. However, even when the length of an admission was known, the child's response to treatment could result in longer hospitalisation and families spending more time and money at the hospital. Even if the child's treatment went according to plan, it was not always possible for parents to predict how they themselves would respond to the experience. The amount of time that parents would need to take off work would be influenced by how long it was before they felt confident about their child's progress and did not feel that they had to be with their child. A father's account indicated that parents would have to balance the competing pressures of their desire to be with their child and the need to continue earning:

> Father:... I had t'first week off, when he were in like, so
>
> Mother: Well, you weren't going to do were you, you were going to have a couple of days?
>
> Father: I were going to have t'first couple of days, till I were satisfied that he were all right, like, then I were going to go back to work, 'cos I have to stand to, like, I hadn't got nowt to stand to have a week off like. So I were there every morning like and through t'day.
> Int. 33:9

Another mother who had planned to stay in with her child found that she could not stay after all and the father took time off work at short notice in order to stay in.

A further source of unpredictability was the costs of eating and drinking in hospital which came as an unpleasant surprise to some families. Parents noticed that they did not receive the staff discount in the canteen, which made their own meals and drinks seem all the more expensive. An enterprising group of parents discovered that a nearby hospital for adults had a canteen that charged lower prices for meals. However, for most parents breaks were a hurried affair and so shopping around was not a viable option: the financial saving of using another hospital canteen would have to be set against the extra time away from their child. Some lived on sandwiches and drinks brought in by their families who lived nearby. However, parents whose families were unable to service them in this way were a captive market for the hospital canteen. Any extension of the child's hospitalisation would add to these expenses and so the unpredictability of a child's condition meant that many parents were making an open-ended commitment to further expenditure.

"From them that hath not": the greater burden of costs borne by low income families

The costs of staying with the child in hospital were not experienced equitably by all parents. Some costs were the same in absolute terms for all families but presented low income parents with more difficulty, for example the low income families found the price of meals was a burden on their finances. More prosperous parents would pay the same prices for the meals but this would have much less impact on their finances. The more favourable conditions of employment enjoyed by middle class parents also reduced the loss of income that they suffered. The bricklayer who described how he stayed off more days than he had intended was spending money in a direct way when he made his decision: if he did not go to work he did not get paid. Potentially he also placed his longer term finances in greater jeopardy because of the damage to his reputation as a reliable and conscientious worker. The difficulty of local economic conditions in the construction industry was illustrated by the fact that he had taken a job in a town thirty miles from home. He discussed the threat of redundancy and the difficulty of finding work with me and so his decision to stay off work must also have involved a calculation about the longer term risk to his job security if he should be regarded as an unreliable worker. These financial pressures were less immediate for middle class workers, for example this teacher was able to avoid any loss of pay:

> Father: Well, different Education Authorities have different views on compassionate leave. I mean Countryside only allow five days per year...so I mean I went to see the Head Teacher about it and he said I would only be entitled to another day and a half with pay. Erm, and rightly or wrongly the pragmatic thing to do in these circumstances is to get a sick note. And, you know, our GP was, was ready to accept that a sick note was necessary
> Int. 26:8

Other middle class parents were able to re-organise their work in order to avoid loss of income or holiday. However, working class parents described the use of annual leave, in some cases for the entire year, meaning that no further holiday would be possible for them. Although there were no lone parents in the main study sample, it is clear that loss of income and holiday would be an even more difficult burden for a lone parent to cope with.

The length of stay could also be influenced by families' access to resources, as the surgeon's comments about criteria for discharge indicated:

> Surgeon: And the other big thing you have to assess is the domestic situation and if they live in Middletown [twenty miles away] and they have no means of transport, then you have to wonder if it's sensible to send them...or in the middle of the country somewhere between here and Far-Town, it's not fair to send them home, unless they're very keen, unless they say "It's all right I'll get my neighbour to bring me back" but if they say "I've got no transport and I'll have to come on the train", then you can't do that.
> Int. 17:4

It was also clear from the surgeon's comments that access to a telephone was important for early discharge:

> Surgeon: ..and they have a direct telephone line to the ward, they don't have to sit and book..an appointment with their GP..that might be three days time
> Int. 17:8

These comments indicated some of the resources that were considered essential by the surgeon. Transport, for example is seen as the parent's responsibility rather than the hospital's and there is an implicit assumption that is the responsibility of the parent to muster the resources required for safe care at home. Those who do not have access to such resources are not in a position to be discharged early and so will incur the expense and disruption of hospital for longer.

An unrecognised burden

Families found that very little financial assistance was available to them. Assistance with the expenses of staying with a child in hospital was sought by some parents but the response that they received was limited. During one interview the local Department of

Social Security office telephoned the mother to reject her claim. Some help was available for a proportion of travelling expenses but not for the living expenses whilst the child was in hospital. It was interesting to hear the mother try to explain that she had incurred extra expenses in hospital. The benefit system includes provision for reducing benefits when a person is hospitalised but the increased expenditure of staying in hospital with a child does not seem to be recognised in the benefit system. None of the family was in paid employment and the father's place on an employment training scheme meant that the family had neither the benefit of his time nor of a full wage.

The consequences of the increased expenditure resulting from staying with the child could be severe, for example one family were threatened with eviction due to rent arrears during the time that their child was in hospital and needed the intervention of the hospital social worker in order to prevent this happening. However, the limited recognition of the extra costs involved in a child's hospitalisation and meagre support available from welfare funds has been identified by Action for Sick Children, a charity that is involved with the parents of hospitalised children (Goulding, 1992). The introduction of the Social Fund in 1988 reduced the financial support available and Shelley (1992) suggested that "social workers can offer very little help or advice to parents".

CHAPTER 7: PARENTS AS CO-CLIENTS

Introduction

In this chapter the experiences of parents who became co-clients of nurses are considered. Mothers and fathers found the experience of living in with a child was often difficult both for practical and emotional reasons. Their involvement in the care of a child who was undergoing unpleasant procedures could cause them distress and disrupt relationships with their children. Parents experienced conflict between their expectations of themselves as mothers and fathers and the expectations of hospital staff for them to function as effective, emotionally detached co-workers. The different socialisation of mothers, fathers and nurses is considered and the distress caused to mothers and fathers by the conflicts they experienced is examined. As a result of their distress parents could feel in need of care themselves. While some parents were able to derive support from their own families, for others this was insufficient ~~and~~ they became co-clients of the nurses. Nurses' accounts of their care of parents and the problems presented to nurses by the needs of some parents for care are discussed. Nurses described the demands for care by parents as unpredictable and this presented problems in the management of the workload generated by parents as co-clients. Ideological differences about the care of parents emerged amongst nurses who disagreed about the importance of the work of caring for parents.

The difficult experience of living in with a child

The hospitalisation of a child is both a disruptive and emotionally laden experience. In addition to the feelings of concern about the child's physical and emotional welfare, parents may also be contending with feelings of anxiety and guilt surrounding the events that led to the child's hospitalisation. The hospital was not an easy place for parents to live. Facilities for the routine everyday activities of washing and eating were not always convenient or comfortable, particularly for mothers or fathers who stayed by their child's bed rather than in the purpose built parents' unit. The experience of living in could be difficult as a result of the emotional environment of the hospital and the concerns of parents for their children's welfare as well as the physical circumstances in which parents lived when they stayed in hospital. The mother of a child who had thoracic surgery described being in the hospital as "pretty awful" and explained what she meant, at a point in the interview when her husband left the room:

> Mother: Geoff [her husband] doesn't realise what it was like because he wasn't there twenty four hours like I was, but I found the emotions you go through whilst you were there, you know you go through so many emotions. It's not only that, you're aware of all the other children there, that they're all ill, there's all this illness around and you think "Oh Crikey, all these children", 'cos. you don't see that here you see. You go to the clinics here and there's probably three or four children waiting outside, but, I mean, just walking through the corridors there, there are all these sick children and you, crikey, all these children ill, you know, it's unbelievable.
> Int. 41:36

This mother's distress arose partly from encountering so many ill children and their families. One response to seeing other ill children is to minimise the problems of one's own child and so to feel reassured that they are not so ill after all. Alternatively the contact with many ill children could lead to heightened concern about one's own child. Either way the problems of other children were visible and difficult to ignore. The mother's comment that her husband did not realise what it was like indicated her sense of isolation and the lack of support that she was able to draw on from immediate family. This mother was at least ninety minutes drive from home and her husband continued to run the family business while she stayed in the hospital with her child. Even mothers who had more support from their families found living in difficult. A mother who was supported by her own mother described responding to leaving the hospital:

> Mother: And on the way home in the car, I just, my mother was with me, I just burst into tears, just floods of tears, and my mother said "What on earth are is wrong with you?" I said "I did so want to get out of there, I did so want to bring her home" I said "but I'm just, I'm so nervous about taking her home"
> Int. 45:26

This mother's account suggested that she was under considerable strain, the full extent of which only became apparent once she had left the hospital. The strength of parents reactions to living in the hospital is presumably dependent on the condition of the child, their social circumstances and perhaps the psychological characteristics of the parent, which varied widely. Some mothers were far from home and the support of friends and family while others lived near the hospital. Some children had been diagnosed as suffering from potentially serious problems, whilst others had come to their local hospital for comparatively minor operations. However, even when circumstances would appear to have been relatively favourable parents could find the experience of being with their child difficult. For example the mother and father of a child who had renal stones were both nurses and both stayed in the hospital with their child. The combination of support from each other, their familiarity with illness and the routines of hospital treatment represents a relatively favourable set of circumstances. In addition, this family did not have other children at home to add to their concerns. The constant contact with a child in hospital was itself a strain for this mother and father. The mother mentioned that it was essential to have a break from their child together:

> Mother: We were getting him dressed, bathing him, anything that he needed, yes...apart from meal-times, that were only time that we left him and we, we thought we must have that break away together. You know, I mean, to start off with he were at that much, that clingy that we had to take it in turns, didn't we, to go down (Father: For a meal) and have something to eat? And t'nurses said "Well, it's just getting you down this, you must have a break off, off t'ward together."
> Int.42:8

For even this family, the experience was a difficult one that made demands on the parents which they found to be a strain.

Shock of seeing child in pain or undergoing treatment

Involvement in the child's hospitalisation included seeing the child in pain or undergoing treatments which could cause parents shock. Some aspects of hospital routine were particularly laden with meaning for parents. The experience of watching the child become anaesthetised was an example of a hospital routine that some parents found shocking and disturbing. The reactions of parents who stayed with children while they were anaesthetised varied widely, with some parents having little to remark on, while others were very upset, for example the father of a child who had elective renal surgery:

> Father: I went with him when he had his first operation, I went down to the theatre room with him, and I mean I cried.
>
> Mother: He came out crying, and I mean that was just in the anaesthetic room. I mean it was sort of a worry really.
>
> Father: To actually stand there and watch your son become so lifeless, do just not here, not there but somewhere, and then all of a sudden there is half a dozen people round, taking him into a room, and do what, basically anything could happen.
> Int. 28:26

The first contact with a child who had returned from the operating theatre could also be a traumatic experience. The mother of a child who had emergency surgery for what proved to be a ruptured appendix described how she first saw her son in the intensive care unit after his surgery:

> Mother: I mean like the pain, for me, seeing him with all them drips in, (I: Mm, must have been a shock, mustn't it?) changing his drips, oh, it were just, it were just, I know I should never go through it again, I don't think I'd survive.
> Int. 48: 5

The sight of a child wearing a mask seemed to be particularly disturbing for parents. The mother of a child who had relatively routine elective surgery described her shock when her child returned from theatre wearing an oxygen mask. She interpreted the mask as a sign that her child's condition was grave and was unprepared for it:

> Mother: Well when I first saw her she had an oxygen mask on her face, and my first thoughts, I don't know why, it was silly really, it was "Oh my goodness she can't breathe by herself she's got an oxygen mask on". I think that panicked me more than anything and I said "Why.."

> Interviewer: 'Cos. you weren't expecting it?
>
> Mother: Yes "Why has she got a mask on her face?" "Oh, well, she's had a long anaesthetic and she just needs some oxygen" and so then I felt all right.
> Int. 45:13

Disruption of contact between parent and child

The altered appearance and fear of hurting the child could lead parents to feel distanced from their children. A mixture of shock and fear could result in parents being very reluctant to make everyday contacts with their children and to think that it would be better to leave the handling of the child to skilled nurses. The mother of a child with learning difficulties who had elective abdominal surgery described her initial fear of hurting her child after his operation:

> Mother: I did everything when, at first obviously when he's all dripped up and things, I'm frightened, a little bit frightened to touch him in case I hurt him or pull anything but gradually, er, when I knew he wasn't in pain, I'd change him, change his nappy, wash what you could get to him
> Int. 25:7

As well as the fear of hurting a child who had an operation wound and equipment attached, parents could be distanced from their child by the distress caused by being with a child in pain. A mother described how she had to have a break from her child while he was in pain with renal colic:

> Mother: Yes, I think it's even worse when you can't do anything for 'em. I mean, I know what pain he were going through. I mean, that first night he war admitted [...] he'd everybody up, he were really screaming and shouting and he were having trouble passing urine and he war, oh, he were really

> irritable screaming and shouting and, and I wanted to scream with him, you know [..] But er, I mean, there's only so much you can stand, you've got to get away even if it's only for a few hours.
> Int. 42:5-6

Unnatural acts: the detachment required of mothers and fathers

Participation in the care of their children in hospital made extraordinary demands of parents. There were occasions when mothers and fathers were required to deviate from their usual nurturing and protective roles and to adopt a detached approach when participating in the care of their children. The mother of a child who had elective surgery to re-implant ureters described how she was instructed to prevent her child drinking:

> Mother: She had a drip, but she was very thirsty, in fact a nurse come with a little sponge and some pink stuff in water, to wet her lips. Well I put this sponge to her lips and she were [makes sucking noise] and sucked it, and I nearly cried, and she was absolutely thirsty but she weren't allowed anything.
>
> Interviewer: When you said you nearly cried then, I mean what was it that was upsetting about that?
>
> Mother: Because I couldn't give her a drink. I mean her mother gives her everything what she asks for, and all of a sudden you've got to say no, and she can't understand it, especially for a drink, I mean. I've never had to say "No, you can't have a drink" before.
> Int. 30:7

The mother found it very distressing to refuse her child something as basic as a drink of water. Her account suggests that the instruction to prevent her child drinking was difficult because it contradicted her idea of herself as a mother who "gives her everything". Detached behaviour was also required when a child was held still during painful or unpleasant procedures. The father of a child who had undergone a hypospadias repair described the removal of the dressing:

> Father: I'd got him like this, held round here [demonstrates], Jill had got his hand, and t'legs were wide apart and there were two nurses there, weren't there, between his legs holding his legs. And he were just whispering in my ear "Daddy don't let them hurt me". My heart was broken, I'll tell you.
> Int. 22:14

Again the father in this account implied it was his idea of himself as a father who protected his child that was challenged by his involvement in the removal of the dressing. Parents usually accepted the need for procedures and adopted the attitude that their role was to support their child and encourage compliance with unpleasant treatments. The mother of a child who had a lump in his thorax removed summed up this attitude:

> Mother: I thought "Well I take him to be immunised, it's awful at the time, but it needs to be done, it's over with in a flash, if you create a mega-fuss it just takes longer". So that was the sort of line we took with Luke. If anybody came and they were taking blood and it was taking a bit of time, we just stood rock firm by him, reassured him, but he could see that it needed to be done."
> Int. 26:24-5

Despite the distress that it caused them, parents generally seemed to believe that it was best if they were involved in procedures that could be distressing for their children. While holding a child during a painful procedure and ignoring the child's appeal for protection went against the grain, it was seen as better than leaving a child to face the experience without a mother or father present. The mother of a child admitted for elective surgery described how she decided to attend the anaesthetic room:

> Mother:[...] and they were saying "Are you sure you want to go with Patricia and see her being put to sleep?" and I really did, I wanted to go. There had been another mum on the ward who couldn't bear the thought of going down, and erm, when the nurse had come back and she'd asked the nurse how he'd been, and she said "Well he did cry a little, and we did have to hold him" and I thought, even if Patricia has to be held or whatever I would like to be the one that does it. I just felt as though I had to be the one with her, that holds her down.
> Int. 45:12

Public responsibility

Parents believed that it was best for their children if either the child's mother or father was involved in their care, including unpleasant procedures. Nurses agreed that children benefited from the support of parents during unpleasant procedures and so involvement in care was a responsibility of parents. However, there were occasions when parents were excluded from involvement in unpleasant procedures. A nurse suggested that parents might not be invited to be present if they were judged to be unwilling:

> Nurse: So you give them almost, you know, the option before they're put in the position where they feel they ought to, and quite a few parents will say, "Oh, I'll just go for a cup of tea now" and there have been a couple of occasions where you've suggested that the parent might like to go for a cup of tea and not actually given them the option of coming in because you know how they'll react in that situation and that they don't want to be in there but they can't actually admit
> Int. 16:9

Apart from believing that they could tell whether or not parents really wanted to be involved in a procedure, nurses believed that some parents undermined the care of their children and made the work of the nurses more difficult:

> Nurse: you can try and say to them, you know, "You've got to make him sit up" and you'll explain the whole thing about having an anaesthetic and how he could develop chest, you know chest problems get a cold or chest infection, and if he doesn't sit up, and he's lying flat all the time, and "But he doesn't want to, nurse, and I don't make him do what he doesn't want to do" and you think "For your child's good", you know, "We wouldn't be doing this if there wasn't a reason for it."
> Int. 27:19

The nurse's comments indicated an expectation that morally competent parents would not question the treatment of their children but accept the good intentions of the hospital staff and co-operate with their instructions. Assumptions about what constitutes morally competent behaviour by parents have been examined in studies of paediatric clinics (Strong, 1979; Silverman, 1987). Characteristics of morally competent behaviour in children's wards identified by Darbyshire (1992) included compliance and appearing willing to help out. In addition to expectations that parents would adopt a helpful role in the care of their children, the data indicate that parents were expected to behave with what was considered appropriate firmness. Failure to do so might lead to the exclusion of parents from procedures which the nurses judged would be easier to complete without the involvement of parents. This could be a high price to pay, some parents described their distress at being outside a room and hearing their child cry out for them. Mothers' and fathers' responsibility to be involved in procedures was therefore discharged in public. Detached behaviour was expected and parents were open to the scrutiny of nurses and sometimes of other parents.

Some of the conduct of nurses was also open to public view and mothers commented on differences between the approaches of nurses and of mothers to children. They observed that nurses adopted a more brisk and determined attitude than mothers when persuasion of children was required. For example a mother described how a nurse had dealt with the child in the next bed:

> Mother: Well that little girl didn't want to get off the bed, erm, when she'd had her drain removed and the drips. "It hurts me, no, no, I can't" and she was just at an age where they can be very sort of, they get in their own mind and they're very awkward. And this nurse said "Yes, come on, you can walk if you try" [...] she didn't physically get her of the bed, but she was determined that that child was going to get off the bed, whereas I would have probably said "Well, we'll try in half an hour" or something like that.
> Int. 45:30-1

The response of parents to such determined approaches to children was not necessarily negative. Parents discussed the difficulties of being firm with ill children and how this led parents to feel torn between sympathy for their child and concern to ensure that medical instructions were followed. Sometimes parents wished that nurs~~es~~ had taken more of the burden of being firm with their children from them:

> Mother: If they said "We're sitting you up in bed" she didn't say "I don't want to sit up". Now if we said "We're sitting you up" "Oh, just leave me another half an hour and I'll sit up then". If they, if they'd have been a bit more firm and come in she wouldn't have dared object.
> Int. 47:25

This preference for firmness from nurses was based on a belief that children would accept unwelcome instructions more readily from a nurse and that this would have less detrimental effects on the relationships between children and nurses than on those between parents and their children:

> Mother: She had about four or five [nurses] that she really took to.
>
> Father: Yes, and it was not always the ones that pussy-footed around either so that's not always the right approach [...]
>
> Mother: [...] because sometimes she needed somebody to just come and say "Right", you know, some of them were more efficient, "Right, you're having it done" because if she thought she'd get out of it she would wouldn't she?
> Int. 41: 21

Private pain

The public responsibility to behave in a detached way resulted in private pain. The distress that mothers and fathers experienced was not usually the subject of open discussion and some suppressed their feelings until after the child's discharge. Decisions to be involved in the care of children who underwent distressing procedures were not without cost to parents. The mother of a child who underwent elective surgery described how she continued to feel distress after she brought her child home:

> Mother: I was an extremely traumatised person when I came out. Just constantly having to hold her down and her screaming and being so frightened, you know, you absorb it because you have to because you're there to help her, but you've then, later on, you've got to deal with something, with all that stuff that you've pushed out. You know, I felt like I was a sponge absorbing all the pain, really.
> Int. 39:9

The different socialisation of mothers, fathers and nurses

Mothers and fathers in the study were not socialised to behave in the detached manner which was required during some of the procedures in hospital. The social expectations of parents are concerned with protection and nurturing and so for parents to participate in care which involved detached firmness with children could both be upsetting for the parents and raise doubts about their moral competence, as this mother's comments indicated:

> Mother: Yes, I helped t'nurses to hold him down. Everybody says: "Oh, I don't know how you could have done that to him." It's got to be done hasn't it?
> Int. 33:23

The mother's comments have a defensive tone, as if she must justify an action which she fears could undermine her moral status. It is interesting that accounts of "being firm" with children often featured fathers in the role of disciplinarian. It seemed more acceptable for fathers to demonstrate the more detached behaviour required in such situations. In some cases it appeared that the father was deputed to go with the child to the anaesthetic room and when the child's behaviour led to problems with compliance it seemed that fathers became more involved in the care of the child. The father of a child who was reluctant to drink as he recovered from a hypospadias repair described how he threatened the boy that he would have to have a drip re-inserted in his arm if he did not drink. The mother of the child left the ward in order for him to make this threat:

> Father: I didn't want to scare him, I mean nobody likes to scare their kid, but I had to scare him and be firm with him, I suppose, to make him realise that he had to eat and drink. [...] All I had to do

> was just to point to the back of me hand and he knew what I meant
> without mentioning needles again.
> Int. 22:18-9

The father's account demonstrates his unease about how his actions might be interpreted. He stressed how he, like any other morally competent parent, was reluctant to cause his child fear and he made clear that this was a considered action, a step that was taken deliberately rather than the result of a loss of temper with a child who was causing frustration and concern. The father was therefore careful to present his actions as the painful duty of a concerned parent, which was necessary for the healthy recovery of his child. The way in which the father described his actions as well as telling a story of an incident indicated the conflict that he felt between the social expectations of a father, as a concerned protector of his child from distress and his perception of the necessity of instilling fear in his child at a time of vulnerability in order to persuade him to comply with the instructions of the nurses in hospital.

While mothers and fathers brought expectations of nurturing and protective roles to unpleasant procedures, nurses brought expectations of and training in detachment. The mother and father of a child who were both also nurses commented on the differences between involvement in care as a parent and a professional:

> Mother: It's totally different when it's your own. Er, we've said
> this a few times haven't we, I meant, it's er, it's different when
> it's your own.
>
> Interviewer: What is it that makes it different then?
>
> Father: Your own blood [laughs]
>
> Mother: I don't know, it's er, it is, it's just different. I mean
> you know they're going to pull through and everything and you

> know how they're gonna come round in Recovery and everything, but even though you know what to expect it's so different wi' your own child, because you're used to seeing him up and running around and everything and then to see him just laid there lifeless and everything it's oh, yes. I were distraught first time weren't I [laughs] Dear me. It dun't get any easier though. No.
> Int. 42:12-3

The detachment of a nurse was therefore necessary for the effective care of children and the emotional involvement of a mother or father could be a hindrance. A mother described how she had decided that most of the nurses were not mothers themselves and suggested that detachment was to be expected from nurses:

> Mother: I felt like a lot of them weren't a lot of them looked young and sort of a bit like, er mechanical, I thought, you know, they didn't really have the, er, I don't know, I suppose like when you're a nurse and, and you see children poorly every day, it can become a bit mundane and like, you're so used to it that you have to tune it out or you'll get upset. But I think that if you are a mother you have to be a bit more sympathetic.
> Int. 46:9

However, the detachment of nurses could also be regarded as excessive and lead to behaviour that parents regarded as unsympathetic to children:

> Mother: [...] there were one nurse in particular, she were t'only one that I didn't really like, she was right rough, you know, "Come on, sit up" and she like dragged him up and I thought "No, please, he's too delicate, you'll snap his legs", it's all I kept thinking about "Please don't snap his legs, he can't have a leg broke" and, yes, she, no, I didn't really like her for the way that, like her attitude towards you, you know...But I mean she was a good nurse and she knew her job."
> Int. 48:4-5

The comment that this was a good nurse despite her roughness suggested that the job of being a nurse did not necessarily require a sympathetic approach to children. The mother appeared to imply that while she would prefer nurses to be sympathetic this was not essential for the performance of the work of a good nurse.

Detachment was regarded as necessary by health professionals. The comments of a surgeon indicate the necessity for separating emotions when technical care is required:

> Surgeon: People often say to me "I don't know how you can operate on babies" and you say "Well, yes, it's er", you're doing it because you're doing it but I don't think I could operate on my own child, I mean I wouldn't dream of it, but I couldn't.
> Int. 17:14

The surgeon went on to explain why parents would not be allowed to watch operations performed on their own children. While this discussion was entirely theoretical because the question would never be seriously entertained in practice, the surgeon's explanation illustrates the notion of detachment that is required of health professionals and the impossibility of parents adopting a similarly detached attitude:

> Surgeon: Because I think that most people find that when it's their child, however well, er trained they are they have an emotional involvement and they can't watch in a dis-attached sort of way. Whereas if you go, you know watching people stick knives into patients' abdomens and taking out their appendix, you don't think anything about it at all but if you actually saw somebody sticking a knife in your child, your emotional involvement comes in.
> Int. 17:13

The socialisation of health care professionals includes training in the management of the emotions that people experience when they encounter disease and death. As part of a study of the socialisation of medical students Fox (1979) investigated medical students' experience of the post mortem examination in their training. Fox suggested that through their experience of the post mortem examination students learned what he called "detached concern":

> "This is the process by which students gradually learn to combine the counter-attitudes of detachment and concern to attain the balance between objectivity and empathy expected of mature physicians in the various kinds of professional situations they encounter."
> (Fox, 1979:56).

The particular importance of autopsies was that these were occasions where the reality of death was encountered by students, perhaps for the first time and where they observed how their seniors approached the task of treating the cadaver as both an object of scientific interest and a person. There are also events in the training of nurses that serve the process of socialisation into the attitudes towards patients expected by the profession. Detachment is regarded less positively now than it might have been in the 1950s when Fox studied the socialisation of medical students and concerns that health professionals have developed a technological view of people have been widely expressed, including in nursing (Benner and Wrubel, 1989). Consequently interest in the study of emotion management in nursing has developed (James, 1989; Smith, 1992). In a study of the socialisation of student nurses that concentrated on the "emotional labour of nursing", Smith (1992) used participant observation and interviews to describe the experiences of a group of thirty one student nurses. Smith described some of the students' experiences of caring for patients who died and it is interesting to compare her account with Fox's study of medical students. In both examples the student was required to confront the death of a patient and to perform functions which combined technical and emotional work. While both the medical students waiting for a post mortem examination to be arranged and student nurses learned about the unpredictability of death, the student nurses were not guaranteed the experience as the medical students were. Nurses would happen upon experiences of the management of cardiac arrest and conduct of last offices by chance. Both groups were expected to confront a potentially distressing experience with stoicism: in both Fox's and Smith's account the suppression of emotions is described. However, Smith described the approach of a ward sister who invited nurses to discuss their feelings after a cardiac arrest with approval, suggesting that in some cases a more open expression of feelings is appropriate amongst nurses in the 1980s than was considered appropriate amongst doctors in the 1950s. Despite these differences, there are notable similarities between the two accounts: both medical students in the 1950s and nursing students in the 1980s recognised the management of their emotions in distressing circumstances as an important part of their professional education and both groups learnt to adopt an attitude of detachment that enabled them to provide technically competent care. Thus health professionals continue to learn to be detached during procedures which are emotionally laden.

In addition to the extreme case of dealing with death, children's nurses need the skills of everyday parenting. An incident which I observed on the ward illustrated the skill of a sister, and the uncertainty of student nurses, in the everyday handling of children. Kevin had spent many weeks in hospital and undergone a number of operations during his two and a half years of life. His family were not with him for much of the time and it was common to find Kevin on a nurse's lap or standing with the nurses chatting. One day when I arrived on the ward I noticed that a student nurse was struggling with Kevin in a side ward. Kevin was shouting and scratching her and her attempts to stop him were ineffectual. One of the sisters arrived for her afternoon shift and stopped the commotion by taking Kevin away to talk to him on his own. Later she returned, cuddling Kevin in her arms. She called the student nurse over and Kevin apologised to her, Kevin then sat on his bed with his Postman Pat book. Later Kevin again started shouting and arguing with a student nurse and the sister again took him aside. After a further period of quiet Kevin lay down in the most public place in the ward, next to the nurses' station. The sister told the student nurses to ignore Kevin and not to reward his behaviour with a cuddle. A male student nurse went to Kevin and not heeding the comments of other students, started to cuddle Kevin. The sister arrived again and took Kevin away. This incident illustrates the uncertain handling of children by inexperienced nurses and the need for firmness in everyday handling which the students had not learnt. The sister demonstrated a skilled approach, dealing firmly but kindly with a child who appeared lonely and unhappy. Parents are used to dealing with such demanding behaviour, which can be a normal part of a child's development. For the inexperienced nurses the behaviour was difficult and they were particularly uncertain of when to be firm with children and when to show sympathy. Their learning about parenting is different to the way that parents themselves learn, because nurses learn to deal with children through their involvement in procedures that require detachment rather than through the normal processes of parenting. Nearly all the nurses were not parents themselves and so they had not developed their knowledge of parenting through personal experience. Thus, nurses are socialised to be detached when children are subjected to unpleasant experiences but may have little understanding of the everyday negotiation of appropriate behaviour with children. However, the skill of the sister who dealt with Kevin illustrated how nurses could become expert in their dealings with children.

Although parents were not socialised into the attitude of detachment that is the norm for health professionals it is interesting to note two cases where such socialisation had been experienced in different contexts. One is the case of the parents who were themselves nurses and who protested that their training and experience did not prepare them for the hospitalisation of their child. They spoke strongly about how different it was caring for their own child to caring for adults in their professional lives. The other example was a mother who referred to her farming experience as preparation for caring for her child in hospital:

> Mother: [..] I've always worked with animals, erm, all my life and I've done things like castrating pigs and things like that [laughs]. I know it's not the same when it's a human being but I did feel as though, erm, things like that have helped me to be able to just, erm, manoeuvre things around a bit and not be frightened of getting near the wound.
> Int. 45:16

The conflict between the social expectations of a parent in everyday life and the requirement to adopt a detached approach during hospital procedures was an important contribution to the difficulties of living in with a child. The various difficulties that arose from the ambiguity of parents' roles, the practical and emotional problems posed by living in a hospital and the conflicting demands of everyday parental expectations and the emotional detachment required during unpleasant procedures meant that some parents were distressed and upset during their time in hospital with their children.

Private arrangements for support

The difficulties experienced by mothers meant that some felt in need of care themselves as a consequence of their involvement in their children's care. When mothers felt the need for support, they turned to their own families first. The mother of a child who had ureters re-implanted electively explained that her husband came into the hospital when their child's condition worsened and linked this to her own need for support:

> Interviewer: did he sort of come in to see you during the time (Mother: Yes), he wasn't staying in the hospital (Mother: No) because he was looking after the other children at home?
>
> Mother: Yes, yes, he came in at night.
>
> I: Right, so he'd come, what, every evening would he?
>
> Mother: And he had er, he had the, she was, the worst day was the Wednesday when she became really ill, so he had Thursday off because I was in such a state [...] he was in all day on Thursday
> Int. 39:12

It was predominantly mothers who stayed in hospital with their children and fathers contributed by substituting for mothers on some occasions and supporting the mother so that she could continue to care for the child. However, leaving work in order to support a mother who was finding the experience difficult would carry its own costs and in some cases alternative arrangements were made. One alternative arrangement was for the mother to be cared for by her own mother:

> Mother: [...] to my mum I was the patient, definitely, erm, my mum knew how worked up I got about hospitals [...] But my mum was, my mum was nursing me, it was always when my mum came "Now are you all right?"
> Int. 45:37

In her account the mother clearly identified herself as in need of care and accepted her mother's definition of herself as the patient. Mothers and fathers were hesitant to cast themselves as in need of support, possibly because they were concerned that this would divert attention away from their child. Some comments suggested that it was inappropriate for mothers or fathers to be considered as "patients" when it was the child who was ill:

> Mother: [...] being a grown woman I should have known that I had to look after myself
> Int. 45:38

Difficulties experienced by parents were a matter of private concern, in the first instance at least and so private solutions should be found because the children had first call on the attention of nurses:

> Father: I think in the overall scheme of things they've [the nurses] got enough to do with looking after the kids, and if the parents can't look after themselves in some ways, then, (Mother: It's tough, isn't it?) it really is tough.
>
> Mother: I mean I wouldn't have expected them to have done anything for me, I must admit.
> Int. 36: 19

In addition to their own families, some mothers found support from other mothers who were living in with their children. A mother whose child had frequently been hospitalised in her local district general hospital described the mutual support of mothers that she experienced there:

> Mother: [...] when I've been in Local Hospital you tend, everybody sort of speaks to everybody, you know, er, there's about three or

> four of you go down together, or you all go for a drink at the same time [...] you talk about your problems, you know, and things like that, like a pressure off your shoulders.
> Int. 29:10-11

Access to peer support depended on the amount of contact that the mother would have with other mothers. Those who were in side wards were often very isolated but even for mothers in the six bedded wards sympathetic contact with other mothers was a possibility but not a matter of course.

The assumption that mothers should look after themselves was shared by nurses, at least in the view of the mother of a child who was admitted for hypospadias repair. This mother felt that her own physical needs were dismissed by nurses:

> Mother: [...] one night my stomach was really upset and I asked if I could have some Setlers or something, and they like "You're not the patient, if you're not well go home". I mean they were really like, "If you're not well you shouldn't be here so go home."
>
> Interviewer: That's what they said? (Mother: Yes) Were they the words...?
>
> Mother: Yes, my husband, you asked for Setlers that night, didn't you? (Father: Yes, yes) And she said, the nurse the nurse that was head at the time, she said "If your wife's not well I suggest she goes home". I mean they weren't sympathetic at all.
> Int. 46:3

It is possible that the reaction of nurses to this mother was influenced by a fear that gastro-enteritis would spread through the ward. There may have been grounds for this fear because it was surprising to find that several parents in the study suffered from vomiting and diarrhoea during their time in hospital. However, there were mothers and fathers who did come to be regarded as clients by the nurses and by themselves. An example of an occasion where a mother felt cared for by a nurse was given by a mother when she explained her praise for a particular nurse:

> Interviewer: [...]so what was it that made her, why you say she was good?
>
> Mother: Because, I'd cried to her and she was really sympathetic and sat down wi' me and got hold of my hand [...] she were caring, she were concerned she was like a nurse should be really.
> Int. 49: 28

The explanation suggested that the help of the nurse was a response to an appeal by the mother and this characterised the accounts of how parents became co-clients. It appeared that mothers and fathers became the object of nursing care as a last resort, when private systems of support were insufficient to prevent distress spilling over and becoming a matter of concern to nurses.

Nurses' care of parents

Nurses agreed that they had responsibilities for the care of mothers and fathers, which included explaining the comments made by doctors, encouraging parents to leave the ward for a break and extended to counselling of distressed parents. This construction of parents as clients is consistent with comments in a recent paper which examined the distress experienced by parents in an intensive care unit. The authors suggested:

> "As parents are often the most important source of comfort to the children, it is critical that paediatric intensive care staff are able to identify the predominant sources of parental distress and

> are able to implement strategies that can help parents to manage these stressful situations in the most constructive way."
> (Haines, Perger & Nagy 1995).

Parents could be legitimately defined as clients in the view of nurses in Studyward as well. In some cases nurses believed that their major efforts were directed to supporting parents and that this could be more onerous than caring for the child:

> Nurse: [...] Erm, you tend to find some that, the child is fine, you know, the child doesn't need anything else from you apart from what you're giving, but you find that the parents need a lot more attention rather than, you know, the child. Erm, just worries and things that sort of come up and it may not be anything to associate with the operation the child's had but sort of other things that come into it. You know, 'cos. just by being a resident parent in hospital, it's sort of come out recently that parents have sort of said it's very expensive to live in hospital and travelling and things.
> Int. 35:6

Although nurses all saw the care of parents as part of their work and accepted that some parents could become the principal client, it was not clear what was the nature and extent of this aspect of their work. Nurses did not appear to have a common view about what the extent of nurses' involvement in caring for parents should be, which parents should be treated as legitimate clients and how this aspect of care should be organised and managed. The descriptions of caring for parents varied principally in the emphasis that nurses gave to this work. It appeared that some regarded the care of parents as a very important part of their role and one which they believed should be expanded but other nurses spoke with less commitment. What was common to all the interviews with nurses was an assumption that parents represented part of their everyday work, for example a nurse described the need to ensure that parents took a break from the ward.

> Nurse: [...] And it's like you can go in and say "Have you had a break yet at all?"
>
> I: Yes, so you'd see that as part of your sort of day's work in a sense?
>
> Nurse: Oh yes, very much so, yes you do, because I mean you are - in a lot of cases the parents are so anxious and so upset, you know, you're baby-sitting them as well as looking after the children [laughs]. You do have to look after them.
> Int. 27:7

The use of the term "baby-sitting" in this nurse's account is striking. It suggests a rather disparaging view of parents as in need of the supervision of a more responsible person. In addition the use of the term "baby-sitting" describes aspects of the nurses' work with parents: nurses responded to the demands of parents rather than planning interventions with them and so their relationship with parents as clients was dominated by unpredictability and the ad hoc negotiation of what was a reasonable demand for the parent to make. The working life of a baby-sitter must have similar characteristics as she waits for her charges to present her with unforeseen demands on which she must adjudicate. There were differences of emphasis in nurses' descriptions of their care of parents. Some nurses believed that spending time with parents was not sufficiently valued by their colleagues. It appeared from some comments that their were ideological differences about the place of the care of parents in the practice of the nurses:

> Nurse: I would say it differs between nurses , erm, I mean supposedly all nurses are good at communicating, but I would say they're not, sometimes. I know a lot of t'time they just see

> the clinical side of things [...] Perhaps they just see it as you know "We're here to do a nursing job", rather than being involved in looking after the parents as well.
> Int. 35:10

These differences of view about the importance of the care of parents had their most concrete expression in the use of nursing time. Nurses who believed that they should spend time with parents in order to develop relationships and prevent crises where the parent became upset felt that their use of time in this way was questioned:

> Nurse: [...] if you're actually teaching somebody a technique or a task, that's acceptable because you are doing something. If you're sitting down, having a long conversation with somebody in a supportive role, and the difficulty is that I'm not sure that people know that's what they do. I think if you ask people they'll say "Well yes of course that's important", but in practice it doesn't happen.
>
> I: Because of other pressures presumably?
>
> Nurse: Yes, other pressures and, again there is still this element that "A nurse is not doing her job unless she's busy".
> Int. 19:9-10

Some nurses suggested that time should be spent with parents in order to assess the needs of the parent for care. A nurse stressed the search for understanding of the concerns of parents and complained that she did not feel that she had the time to make such assessments:

> Interviewer: You think it's an important part of the job that you're not able to do enough of?
>
> Nurse: Yes, yes. 'Cos. I think a lot of things come out when you're just sit and talk on an informal basis rather than, you know, you're sitting down and just asking certain questions.
> Int. 35:8

However, the interview data and observation of discussions during shift hand-overs suggested that the care of parents was not usually planned on the basis of assessments of need but took the form of particular nurses responding to immediate needs presented by parents. A senior nurse, who shared responsibility for managing the ward, appeared to agree that there was limited time available for parents when she suggested that a skilled approach could mean that nurses could care for parents whilst involved in other activities:

> Nurse: [...] But when you actually go in and do that sort of thing you are actually killing so many birds with one stone, you're seeing to the child, you're delivering the care, you're counselling the mum at the same time. So you're actually doing all so many different tasks all in one go. So I mean you might have had to go in and sit and talk to that mum anyway and it would have taken ten, fifteen minutes, but at the same time you've changed that baby, you've fed that baby, you've done its obs., and you could have done everything and just have been sitting and talking to the mum at the same time. So it's a case of organising yourself really. And it comes with practice.
> Int. 18:9-10

This would suggest that the care of parents would be fitted in when possible, that it was work that did not have a space of its own but was contingent on the circumstances of the ward. However, this same senior nurse acknowledged that it was not always possible to predict the work generated by parents and organise care around other responsibilities:

> Nurse: I've gone in to read a drip on night duty before now and been in there three hours. But that's part of it. That is part of our role, you know, part of it is counselling and it's an important part. So I would say it's taking an opportunity to give the parents the extra support.
> Int. 18:13

Mothers and fathers were in an ambiguous position as co-clients. They could become co-clients if nurses could fit care of parents in with their work with children or their problems could become public and lead to recognition as co-clients. However, there was no explicit recognition of them as co-clients and the status of co-client was an ad hoc status with no formal recognition, so that it appeared to be in the gift of nurses who happened to be particularly sympathetic.

Unpredictable demands for time

Nurses suggested that the demands of parents for time were unpredictable and presented them with problems in managing their work. One cause of the unpredictability of parents' needs was the unpredictable course of their child's diagnosis, treatment and recovery from surgery:

> Nurse: [...] I mean, like this morning, I spent quite a bit of my time in one of the cubicles with a mom because she was just so upset. She'd had no sleep last night, her child was poorly this morning, erm, she didn't understand why because he should be getting better, he'd had his operation four days ago. And if everything had gone to plan, yes, he should have been up and about and feeling a lot better, but he was quite poorly there this morning so.
> Int. 27:5-6

The demands on nurses were also unpredictable because they arose from the process of parents coming to terms with the child's illness, treatment and future. For example, although a mother might be keen to take a child home, the prospect could also seem daunting, particularly if the mother was adjusting to her child's stoma:

> Nurse: [...] I said er that it wasn't a good idea if he went in the bath in the evening, he'd better go in the bath the next morning, because we'd got his stoma bag on him and it would fall off and it wasn't good for his skin. And five minutes later I found her crying in the room and I spent, you know, like three quarters of an hour just sitting in this room, listening to her pouring out all these things, all these big major problems to her about the care of her child when she went home, and we were a few days towards going home.
> Int. 40: 6-7

Despite the claims of nurses that such incidents were unpredictable it does not seem surprising that a mother would react in this way to the prospect of caring for a child with a new stoma at home. It could be argued that this incident arose from a lack of planned care of the mother as she prepared for the discharge of her child. While it is possible that a more carefully planned approach to the care of parents might have prevented some of the incidents which were described, the perspective of the nurses seemed to be that parents presented problems in a haphazard and unpredictable pattern. Therefore the needs of parents could by their nature arise at times when it was difficult for nurses to give time:

> Nurse: I mean if they really want to talk to you, you can almost — see 'em wanting to do it, and yet you feel awful when you can't give 'em that time, or some, you're interrupted, [...] or you know and then you try and go back but you've missed it, sort of thing, you can't get back in to what you were talking about.
> Int. 37:20-21

If the care of parents were to be systematically assessed there would be consequences for the staffing of the ward. More nursing time would need to be allocated to the assessment of parents and for the implementation of the plans of care that would be devised.

The unpredictability of the demands made by parents was explained by some nurses as arising from the personalities of particular parents:

> Nurse: some parents get hysterical at the slightest little thing. Yes, definitely. You know, I mean, I think there was, earlier this week there was a mother here inconsolable, floods of tears for about forty five minutes, because her child was having a blood test done. You know, it depends very much on their personality as to how they cope with things [...] it just means you're sitting on after you're supposed to be at home, doing Kardexes and catching up on all the paper-work and things like that.
> Int. 27:8

If the behaviour of parents is explained by their personalities then efforts to assess needs and plan care will presumably be doomed to failure. The comments of this nurse suggest the alternative ideological position: that some parents presented difficulty not as a reasonable response to difficult circumstances, which could be avoided by assessment and planned care, but as the unreasonable behaviour of people who are "hysterical", and who cannot easily be helped.

The assessment of parents

In view of the difficulties caused for nurses by the unpredictable demands made on them by parents, it is perhaps not surprising that judgements were made about which parents were likely to present the nurses with demands for time. Parents were assessed by criteria which included rationality, intelligence and whether or not they were "sensible".

"Irrational" parents

Parents who showed what was considered to be excessive anxiety were characterised as irrational and difficult to deal with:

> Nurse: And she was difficult - she's a very uptight, very anxious, quite unreasonable at times. Not aggressive, although she has an unfortunate manner of coming across aggressive.
> Int. 19:1

The different tenses used in this quotation suggest that the nurse saw the characteristics of being "uptight" and "anxious" as traits in this mother rather than as a state in response to particular circumstances. The construction of anxiety as a trait was also implied when the response of this mother to particular equipment was mentioned:

> Nurse:...it was unfortunate that she does have a phobia about the drips, machines, drains and it was unfortunate that the once or twice she did leave him something drastic happened while she was gone.
> Int. 19:1-2

Even the experience of something "drastic" happening was not a sufficient explanation for this mother's response, which was characterised as a "phobia". The suggestion that the problem in this relationship was that something was wrong with the mother reduces the responsibility of the nurses to the level of dealing with a problem mother, rather than of dealing with a problem in the relationship between the nurses and the mother. Professionals are in a position to use diagnostic labels in a way that undermines the credibility of a mother and identifies her as the problem. The characterisation need not be as a person with a mental health problem, the behaviour of a parent could also be attributed to "mood":

> Nurse:...And you know you'd be trying to write a Kardex, 'phone a doctor, you know talk to another parent, and he'd be behind me wanting to ask another question. And by the end of the day I'd be like, bring me a wall I need to bang my head, because he's driving me crackers. [...] And I just happened to be around when dad's in this mood or whatever.
> Int. 21:12

The use of the word "mood" implied that the state was not a permanent trait but also suggested that the father's behaviour was arbitrary, that he had was asking questions because of a whim rather than that his response that was explicable and understandable.

The characterisation of some parents as problematic was shared in the accounts of some parents. This mother was responding to a question about what she felt nurses should be taught about caring for parents:

> Mother: Erm, just to listen to parents more. I mean yes, you will get your fussy ones, but I think you'd be able to know your fussy ones from the ones that mean business.
>
> Interviewer: Yes, that's the thing that would have made most difference to you, if you'd felt more listened to?
>
> Mother: Yes, if they'd listen to me.
> Int. 31: 137

The mother's conviction that the "fussy" parents could be separated from the ones who "meant business" was matched by her conviction that she belonged to the latter group.

Relations with parents could become strained. A nurse described one mother in a side-room and suggested that nurses avoided contact with her:

> Nurse:...But people were put off going in because of what happened when they went in. I mean if it was a situation where the child was anxious but mum was perfectly rational, then that wouldn't put you off because you could chat to t'mum...
> Int. 37:6

"Unintelligent" parents

During the shift hand-overs comments were often made about parents who were deemed to be "unintelligent". A variety of euphemisms were used on these occasions but there was no doubting the meaning, and nurses would helpfully list the various phrases used to identify parents who were regarded as being stupid. The context of such remarks was usually that a mother or father had found it difficult to understand an explanation that was regarded as simple by the staff. There was unease amongst some of the nurses that such judgements could be unprofessional and mistaken and that parents would be treated inappropriately as a consequence:

> Nurse: I came on at half-seven this morning and this mum asked me where t'toilet was.[...] and apparently she'd told her three times where it was [...] It's quite disorientating - we know where t'toilet is but when you've been in a day and come out again you can be quite thrown really can't you [...] and Mary mentioned something about "She'd only got one neurone" or something, you know [laughs]. And like when Angela said in report today, somebody'd be dangerous if they'd got a brain [...] I know we say it jokingly, but when students are there I think it's, it's not on really.
> Int. 37:8

“Sensible” parents

The descriptions of parents as lacking in intelligence, or being excessively anxious were contrasted with an ideal “sensible” parent who was characterised as co-operative, accepting of the advice of health professionals and generally presenting few problems to nurses. The characterisation of some parents as unintelligent and others as over anxious echoes the judgements made by paediatricians in out-patient clinics (Strong, 1979) and by nurses in children’s wards in Scotland (Darbyshire, 1992). However, the characterisation in the study ward was particularly associated with the potential construction of parents as co-clients, in need of the care of nurses.

Responses to “difficult” parents

Parents who nurses found to be difficult to deal with could provoke very strong reactions. A nurse discussed how the mother of a child who had an intravenous infusion into a scalp vein repeatedly asked about the need for the infusion:

> Nurse: [...] everybody that went into that cubicle if they hadn’t been in before got asked could this drip be taken out, and she got exactly the same argument from everybody. Went through the whole explanation again [...] she knew all this before and she gave her consent for it but she just decided that she didn’t want this [scalp infusion]
> Int. 27:17

This mother had been discussed during a lunch-time shift hand-over. The nurses who were working the afternoon shift were warned that the mother would ask them the same question and the reason for the infusion was rehearsed to prepare them before they met the mother for the first time. There was a suspicion amongst the nurses that some parents would attempt to catch the nurses out by repeatedly asking different members of staff the same question:

> Support Worker: Yes, but they ask different people the same question to see if they get a different answer.
>
> Interviewer: Right, so you feel like you're sort of waiting to be caught out?
>
> Support Worker: Yes, yes, they're trying to catch one of us out, yes.
> Int. 34: 9

Managing the demands of parents

Parents presented a potential threat to nurses' control over their workload because of the unpredictability of their demands for nursing time. The unpredictability of the demands made by parents meant that they must all be regarded with caution, because all had the potential to make demands that could make the workload of the nurse unmanageable. The problem faced by nurses was the loss of control of the demands on their time because nurses were faced with the constant threat that parents would become primary clients, taking up time by demanding the empathy and energy of nurses who are required to share in their sense of anxiety and fear and to reassure them. The work of the children's nurse can be seen as involving a struggle to keep this tide of demand at bay in order to make the working life of the nurse manageable and to avoid being flooded with the demands of parents. The ambiguity of parents' roles as co-workers and co-clients could therefore be a consequence of nurses efforts to retain control over their working lives.

Becoming a co-client: problems for parents, problems for nurses

Involvement in the care of sick children can be a distressing experience. Some of the mothers and fathers in the study experienced considerable distress, particularly when they cared for their children during unpleasant procedures. The need for efficiency and detachment during such procedures could conflict with the roles for which mothers and fathers had been socialised. Mothers and fathers are not like other workers in hospitals who have been socialised into roles which enable them to maintain detachment as well as concern. The distress experienced by mothers and fathers contributed to their need for care themselves. However, the position of parents in hospital was ambiguous and there was little clarity about when a parent could expect to be regarded as a legitimate focus of nursing care. The uncertainty about the nature and extent of parents' entitlement to be considered as co-clients was shared by both nurses and parents. There was no systematic assessment of parents' needs and it appeared that parents were cared for on an ad hoc basis when their distress demanded an immediate response from nurses. This meant that nurses experienced the demands of parents for care as unpredictable and presenting management problems. Both parents and nurses could benefit from clarification of the nature and extent to which parents can become legitimate co-clients, assessed and cared for in a planned and systematic way. One consequence of such a clarification could be to identify a need for more nursing resources in order to care for parents as well as with them.

CHAPTER 8: FINAL DISCUSSION AND CONCLUSIONS

Introduction

In this concluding discussion the methods used in the study are reviewed and the implications of the findings are considered. This discussion develops from the review of the literature (pages 4 to 61) and the presentation and discussion of findings (chapters 3 to 7). Implications for health care services and nursing are considered and recommendations are made relating to research, education and practice.

Methods

This study has indicated the value to evaluation of health care for children of conversational interviews conducted with families in their own homes after discharge. Although parents were reluctant to appear critical of hospital staff, when given opportunities to tell their whole story and to explain problems they had experienced in context, parents provided detailed accounts which identified unsatisfactory aspects of the service. Where criticisms of the service were made these were often qualified by explanations of the good intentions of the staff and the lack of choices experienced were excused by reference to the staffing levels. It was not necessary for parents to make outright criticisms of the service that they experienced in order to identify inadequacies for example the parents who explained why they had to buy cans of drink for their child did not express this in terms of dissatisfaction, they simply told the story of their experience.

The study has also demonstrated the important part that participant observation can play in conjunction with interviewing. Observational data was useful in its own right and enhanced the quality of data obtained from interviews.

User satisfaction has become an increasingly important concept in health care. There are problems of definition of the terms such as "consumer", "user" and "satisfaction" which are accentuated when the terms are used in the context of hospitalised children. This study has demonstrated that conversational style in-depth interviews, supported by participant observation and review of documents can provide useful accounts of parents' experiences. In particular such accounts reveal the extent to which users felt that choices were available to them about their involvement in care.

Limitations of the study

The aim in this study has been to provide a detailed account of the experiences of a group of parents. Inevitably the sample size is small in comparison to the total population of parents of hospitalized children. Particular features that limit the representativeness of the sample are that it was drawn from a children's hospital, which is a more specialised environment than the district general hospitals where many children are cared for, that all the participants had to speak English and that the sample was drawn from the case-load of one consultant who were admitted to one surgical ward. These characteristics of the sample limit the direct generalisability of the study and in considering the implications of the findings outside the study ward it is necessary to give consideration to differences of context.

Qualitative analysis of data is a process that requires the researcher to make choices about which aspects of the data set to concentrate attention on and which to give less attention to. The results of these decisions about the importance of different parts of the data are visible to the reader of an ethnographic study but the process by which they were arrived at is not. In order to illuminate the process by which decisions were made about the importance of aspects of the data in this study three criteria that guided concentration on aspects of the data are explained below. The criteria were that the topic was important to participants, that a sufficient range of accounts were given to support detailed analysis and that the topic was of clinical importance.

The first criterion was that a topic was judged to be important to participants. The judgement of whether a topic was important to an individual participant was made by considering the strength of feeling with which the topic was discussed and the extent of the discussion of this topic by the participant. The judgement about whether the topic was important amongst the group of participants was made by considering whether the topic was discussed by other participants. Because the home circumstances of families differed and the pattern of each child's hospitalisation differed it was quite possible for some topics to be of importance for some participants but not for others. Thus, the assessment of what was important was a qualitative process rather than a quantitative one, because it involved judgements about the context of individual participants' comments rather than on counting the occurrence of topics in the data.

The next criterion was that a range of comments about a topic were made which was sufficient to make comparisons between accounts and so to explore similarities and differences in the accounts of a group of participants. The purpose of this criterion was to ensure that a detailed analysis of a range of views could be conducted.

Finally, there was an element of judgement about whether the topic was of clinical importance in the provision of health services for children and their families. A purpose of the study was to inform nurses about the experiences of parents in order to assist nurses and other health workers to better meet the needs of parents. Thus judgements were made about whether the topic had implications for the provision of services in the broadest sense.

The analysis will have been influenced by the selection of these criteria and by the way in which judgements were made about particular aspects of the data. It is possible that a different researcher could have decided to concentrate on different aspects of the data set. The application of these criteria will also have been influenced by the experiences and professional orientation of the researcher. My experience as a children's nurse will have influenced my assessment of what was important to mothers and what was of clinical significance and different judgements might have been made by a researcher with a different professional orientation such as a surgeon or a social scientist. Such differences between individual interpretations of what is important are an essential feature of ethnography both because the volume of data that are generated by such studies requires some concentration on what is judged to be important and because the researcher is part of the world that is studied. Judgements about importance are inevitably personal to some extent. The utility of the concepts of "plausibility" and "credibility" proposed by Hammersley (1991) and discussed in chapter 2 (page 108) is that they guide the process of reflexivity that is required in qualitative analysis. As the researcher makes decisions, the judgements that are made are considered as they would be seen by an audience of scientists and the decisions that are presented are those that would be plausible and credible to this informed audience which the researcher has in mind. Readers are like analysts in that they must make their own judgements about the ethnographic studies that they read. The reader of this study is asked to bear in mind the possible influence of the background of the researcher on the process of analysis. A limitation of the study is that it is not directly generalisable as an explanation of the experiences of all parents of hospitalised children but a claim for validity can be made which rests on the strength of the plausibility and credibility of the analysis.

Findings

Throughout the duration of this study increasing emphasis has been placed on the consumer in health care and consumer participation in the commissioning and operation of health care services. Government recognition of the importance of the consumer was indicated by the publication of a Patient's Charter in 1991 (Department of Health, 1991) and the subsequent publication of a revised charter in 1995

(Department of Health, 1995). The empowerment of consumers or users has become a major feature of discourse in health policy today. There are difficulties in defining who is the consumer in many areas of health care (Blaxter, 1995) and this is particularly true of the care of children in hospital. Users of hospital services for children include parents and children but the care of children is also a responsibility shared by a wider society and regulated by the community, most notably through the Children Act, 1989.

Despite the strong emphasis given to consumerism in health policy parents did not emerge from the study as confident, active consumers of health care services. They had limited opportunities to communicate their views to hospital staff and to share in decisions about the care of their children. Whilst it is customary for parents to be involved in the care of their children in hospital, there is little evidence that they are empowered participants in care. Darbyshire (1992) suggested that nurses and parents became friends during long admissions of children and that nurses adopted a "gaze of empowerment". Reliance on this process of the development of relationships over time is inadequate because admissions are likely to become shorter rather than longer and for the majority of parents it is the early part of their admission to hospital that is likely to be most dis-empowering, because this is when their child is likely to be most ill and they are accustoming themselves to the new world of living in hospital. The evidence of parents' accounts in this study is that it is unwise to assume that the behaviour of nurses will always be empowering to parents without intervention and that greater awareness will automatically lead to changes in practice. The record of responsiveness of services for children to the demands of parents and other interested groups is not particularly impressive, as the slowness of progress in the implementation of the Platt report (Ministry of Health, 1959) demonstrated. Education could prepare nurses more effectively to respond to the needs and wishes of service users.

The involvement of parents in the care of their hospitalized children means that there is a need for a reconsideration of nursing. The attempts that have been made to develop new models of children's nursing (Casey, 1988) and to advance family nursing as a concept (Whyte, 1992) indicate that there is dissatisfaction amongst children's nurses with their current conception of their role. However, the models of children's nursing that have been advanced are not satisfactory because they do not address some of the important elements of parents' experiences discussed in this study, such as the distress that parents can experience as a result of their involvement in care.

More active attempts could be made to empower parents in hospital. There is certainly a need for better facilities for parents on wards as has been identified in previous research and official reports (Thrones, 1983; Audit Commission, 1993). It can only be dis-empowering to rely on sharing the bathrooms and toilets provided for children and to have to leave the ward in order to have a hot drink and something to eat. In addition to the organisation of the physical environment, more consideration could be given to communication of information between nurses and parents. Much of the communication of expectations to parents appeared to be implicit and indirect. Parents could also be given more opportunity to express their own views to hospital staff both through individual conversations and possibly also through group meetings between parents and nurses. There are consequences to such empowerment of parents. Parents and nurses in the study suggested that the level of staffing was inadequate to ensure the safe care of children and that the contribution of parents was essential to ensure the surveillance of children. If nurses believe that they have no alternative but to rely on parents then it would not be surprising if they were to avoid communication about such potentially contentious topics. There are potential resource consequences of responding to parents' comments which would require a response if attempts to empower parents were genuine.

It appears that parental involvement in care has contributed to improvements in efficiency in hospital care both because parents contribute to the work of caring for their children in hospital and because children can be discharged earlier if their parents can care for them at home. However, calculations of the costs and benefits of parental involvement in care also need to take account of the costs to the hospital and to parents of their involvement. There were financial costs to parents that arose from travelling and living in hospital was expensive for some parents. In addition the experience of involvement in care could be distressing and impose personal costs on parents and result in demands on the time of nurses. It is unclear whether there are long term effects on parents' health as a result of such experiences.

Parents had an ambiguous position in the hospital, where they were neither fully co-workers nor fully co-clients which meant that it was difficult to establish the legitimacy of parents' own needs for care. Hospitals are focused on patients and in children's wards the patient is the child. In the internal market of the NHS the hospital has a contract to provide care for the child and it is the child who has a bed and a set of medical and nursing notes. While the child has been the subject of examinations by various professionals, who could include GPs, Accident and Emergency or outpatient staff, in order to legitimate admission and treatment, the parent has not been through a referral process. However, parents could have considerable needs for care themselves and nurses suggested that in some cases parents needed more care than their children. The difficulties associated with living in hospital and of involvement in unpleasant procedures contributed to these needs. Some families were able to provide support which prevented the needs of parents becoming obvious but other parents came to be considered as co-clients. This re-construction of the parent as co-client appeared to happen when family support was insufficient and parents made active demands on the time of nurses. Although there were discussions during hand-overs about particular parents, there was no evidence that nurses made systematic assessments of parents' needs.

The entitlement of parents to care could be made more explicit if an assessment was made of their needs and a plan of care was agreed for the parent as well as for the child. If this implied that more resources were required to provide this care then the contract between purchaser and provider would have to allow for them.

Although it is common-place to describe mothers as "experts" there has been little examination of the nature of mothers' expertise in the assessment of their sick children. An important feature of the experience of some families in this study was the difficulty experienced in gaining access to treatment for their children. For some families passage through systems of referral was speedy and efficient but a group of mothers described difficulties they experienced in convincing health professionals of the seriousness of their children's problems. Mothers' descriptions indicated the high degree of skill that they had developed in the assessment of their own children. Mothers observed subtle changes in their children's appearance and behaviour and became concerned when there was deviation from the norm for their own child. It could be very difficult to persuade health professionals of the significance of such assessments and to gain access to treatment for children. Despite the fact that all the children in the sample had been admitted to hospital, mothers believed that their children's access to care had been delayed or limited because they could not persuade professionals of the seriousness of a problem that they had noted in their child. The difficulty of persuading professionals appeared to arise from differences in the nature of professional and maternal knowledge. Mothers observed deviations from the norm for their own children and their knowledge was firmly rooted in the private sphere because it developed from extended close contact with their children. In contrast, professional knowledge is based on observation of deviation from the norm for a population and is located in the public domain. The meeting of these two forms of knowledge made it difficult for mothers to persuade professionals and presumably presented professionals with the problem of interpreting mothers' accounts. While previous studies have stressed the value of maternal observations (Spencer, 1984; Cunningham-Burley, 1990) the differences between maternal and professional knowledge about when a child is ill have received little attention. It has been suggested that lay knowledge about health and illness presents both epistemological and political problems for medicine (Williams and Popay, 1994). The epistemological challenge arises because knowledge that arises from experience of illness can challenge established medical understanding, based on natural sciences. The political challenge arises from disputes about what constitutes a socially recognised illness. For mothers in this study the concern was a very practical one: they were worried about their children and they had difficulty persuading professionals that their concerns were justified and in some cases persuading their General Practitioners that it was the child who needed treatment rather than an anxious mother. Mothers suggested that one of the problems that they faced was that professionals made judgements which influenced the credence that was given to the accounts of mothers by professionals. It was noted that a textbook advised GPs to judge whether the mother or her child was the problem, which suggests that it is not only mothers who believe that judgements about them affect whether or not their views are taken seriously (Freeeling and Harris, 1984). Thus there are concerns about equity of provision as well as access because those mothers who are judged to be more credible will gain access to care for their children more easily than those who are not. Problems of equity could also be expected to arise when families whose first language is not English or who come from minority ethnic groups are involved in such encounters.

Health professionals who interpret mothers' observations and assessments of their children are faced with the challenge of matching two different forms of knowledge in order to make appropriate decisions. Further study of how mothers assess their children could lead to a better understanding which would help professionals to resolve the tensions between different forms of knowledge. It is also possible that such an understanding will reveal epistemological and political disputes that are suppressed or invisible at present.

It is apparent from the literature that parents have had few opportunities to contribute to the development of the policy of parental participation in the care of hospitalised children. This study has contributed to the process of involving parents in the development of the policy by providing a detailed account of the experiences of a group of mothers and fathers. The particular contribution of this study has been to identify themes that have implications for practice, education and for further study. These include problems that nurses and parents experience in sharing care, the differences between mothers' and professionals' knowledge and the difficulties that this caused for mothers and professionals, the social and personal costs to parents of involvement in their children's care and problems experienced both by nurses and families when parents need care themselves. These themes might seem familiar to parents who have participated in their children's hospitalisation and to nurses from their everyday practice However, while these themes might be familiar they have not been the subject of attention in the literature.

Recommendations

Education

Pre-registration education could prepare children's nurses to care for parents as well as children. Firstly such preparation could raise students' awareness about the experiences of parents so that nurses have an understanding of what parents might be experiencing. In addition, education could prepare nurses to respond to the needs and wishes of the parents of children in hospital. Post registration education could also assist trained nurses to reflect upon their practice and meet these objectives.

The education of all health professionals could prepare General Practitioners, Accident and Emergency and other hospital doctors and other health professionals to understand the nature of maternal knowledge and to respond appropriately to the concerns of parents.

Organisation of hospitals

Parents' roles in hospital could be made less ambiguous. Beds, toilets and bathrooms should be provided for parents' sole use and should be designed to ensure that their basic needs for privacy and security are respected. The provision of these facilities would explicitly acknowledge the place of parents in hospital. Hospital canteens should offer the same reduced rates for food and drink to parents as are offered to staff.

Simple details about the location of facilities and ward rules should be made available to all parents, ideally in the form of a simple leaflet that makes clear to parents what they can and cannot do. Best practice would involve parents in the drafting of a leaflet. In addition parents could be given more specific information about what to expect when their child is involved in specific procedures, such as return from the operating theatre or removal of drains.

An assessment could be made and a care plan devised for parents as well as their children. An agreed period of time could be set aside each day for each parent to meet with their Named Nurse to talk about their own needs. There should be facilities for referral to other agencies or professionals if needs are identified which are too complex or time consuming for nurses to meet within their work.

Research

Further research is important in order to improve understanding of:

- the experiences of families from minority ethnic groups
- appropriate skill mixes and staffing levels in children's wards
- how mothers assess when their children are ill
- which methods of organisation of care are most effective in meeting the needs of parents as well as children.

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APPENDIX 1.

Letter to participants

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Dear

I would be most grateful for your help in a study that I am conducting into the role of parents on the children's ward. I wish to interview individual parents and nurses about the things they do on the children's ward. The purpose of this study is to increase understanding of nurse-parent relations and it is hoped that this will lead to improvements in the quality of care.

The interview will take the form of a conversation and will take approximately an hour of your time. I would like to tape record the interview in order to avoid taking notes during our conversation. Interview material will be treated as strictly confidential and will only be available to myself and my research supervisors. The hospital and participants in the study will not be identified in any report of the study.

I am a children's nurse myself but I am not employed by this hospital and your decision about whether to participate will have no influence on the care that your child received.

Please do not hesitate to ask me any questions about the study.

Yours sincerely

Peter Callery
Research Student

APPENDIX 2

Sample off duty sheet from Study Ward

SAMPLE OFF-DUTY FROM STUDY WARD

				July																				Aug							
				12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	1	2	3	4	5	6	7	8
	GRADE		HRS	M	T	W	T	F	S	S	M	T	W	T	F	S	S	M	T	W	T	F	S	S	M	T	W	T	F	S	S
Sister	G	Sister	37 5	E	M	M	E	M	DO	DO	E	E	M	DO	E	E	M	SD	SD	M	E	DO	DO	DO	DO	DO	E	E	M	M	E
Sister	F	Sister	37 5	M	DO	DO	M	E	M	E	M	M	E	E	M	DO	DO	SD	SD	DO	DO	SD	SD	BH	H	O	L	I	D	A	Y
Staff Nurse	E	Staff Nurse	37.5	DO	DO	DO	M	N	N	N	DO	DO	BH	M	BH	M	E	SD	SD	M	DO	DO	E	M	N	N	N	N	O	O	O
Staff Nurse	E	Staff Nurse	37 5	H	O	L	I	D	A	Y	H	O	L	I	D	A	Y	DO	DO	M	E	E	M	E	M	E	M	DO	DO	E	M
Staff Nurse	E	Staff Nurse	37 5	M	M	E	E	M	DO	DO	N	N	N	N	N	N		SD	SD	DO	DO	DO	DO	DO	DO	E	M	M	E	M	DO
Staff Nurse	E	Staff Nurse	15	-	-	6 30	-	6 30	6 30	-	6 30	6 30	BH	-	-	-	-	H	O	L	I	D	A	Y	H	O	L	I	D	A	Y
Staff Nurse	E	Staff Nurse	37 5	MAT	ERN	ITY		LEA	VE		/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Staff Nurse	E	Staff Nurse	37 5	N	N	N	DO	DO	DO	M	-	9	9	8	COU	RSE	-	S/D	S/D	E	M	DO	N	N	N	N	DO	DO	E	DO	DO
Staff Nurse	E	Staff Nurse	37 5	H	O	L	I	D	A	Y	H	O	L	I	D	A	Y	SD	SD	DO	M	M	DO	E	E	DO	DO	DO	N	N	N
Staff Nurse	E	Staff Nurse	37 5	E	E	M	DO	E	E	DO	M	DO	DO	N	N	N	-	SD	SD	DO	DO	E	E	M	M	M	E	DO	DO	E	M
Staff Nurse	D	Staff Nurse	37 5	M	E	M	DO	DO	M	E	E	M	E	M	E	DO	DO	SD	SD	N	N	N	N	N	DO	DO	DO	DO	DO	DO	E
Staff Nurse	D	Staff Nurse	37.5	DO	DO	E	M	M	E	M	DO	DO	M	E	M	E	M	SD	SD	E	M	M	DO	DO	E	M	M	E	M	DO	DO
Enrolled Nurse	D	Enrolled Nurse	30	CON	VER	SION		COU	RSE		/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Enrolled Nurse	D	Enrolled Nurse	30	DO	DO	DO	DO	N	N	N	N	N	N	DO	DO	DO	DO	H	O	L	I	D	A	Y	H	O	L	I	D	A	Y
Nursing Auxiliary	N/A	Nursing Auxiliary	20	-	-	N	N	-	-	-	-	-	-	-	N	N	-	-	-	-	BH	BH	-	-	-	-	N	N	-	-	-
Support Worker	S/W	Support Worker	25	E	M	M	DO	DO	E	M	M	E	E	M	M	DO	DO	SD	SD	BH	BH	DO	DO	DO	E	E	DO	DO	E	M	M
Support Worker	S/W	Support Worker	37 5	M	M	E	E	M	DO	DO	E	M	M	DO	DO	M	M	SD	SD	M	M	M	DO	DO	M	M	E	M	M	DO	DO
Support Worker	S/W	Support Worker	15	-	-	-	-	E	M	-	-	-	-	E	-	E	-	SD	SD	-	-	-	-	-	-	-	-	-	-	E	E
Ward Assistant	W/A	Ward Assistant	25	M	M	M	M	M	DO	DO	M	M	M	M	M	DO	DO	SD	SD	M	M	DO	DO	DO	M	M	M	M	M	DO	DO
Nursery Nurse	N/N	Nursery Nurse	37.5	H	H	H	H	H	DO	DO	DO	DO	M	M	M	M	M	SD	SD	M	DO	DO	M	M	M	M	M	M	BH	DO	DO
TOTALS M		TOTALS M		3/	2	3	2	3	2	2	2	2	2	2	2	1	2	ST	UDY	2	3	2	1	2	2	2	3	1	2	2	2
E		E		2	2	2	2	2	2	2	2	1	2	2	2	2	1	DA	YS	2	2	2	2	2	2	2	2	2	2	2	2
N		N		1	1	1	1	2	2	2	2	2	2	2	2	2	0	-	-	1	1	1	1	1	2	2	1	1	1	1	1

KEY: M = Morning shift
M = Morning shift
E = Evening
N = Night
DO = Day off
SD = Study Day

APPENDIX 3

Characteristics of children in the sample

Characteristics of the sample: the children

Operation/diagnosis	Elective/ Urgent	Child's age (years)
Interviews 20 - 26 (exc 21&23)		
Benign tumour	Urgent	2.5
Hypospadias	Elective	3.5
Head injury	Urgent	4
Pyeloplasty	Elective	5/12
Fundoplication	Elective	13
Interviews 28 - 32		
Re-implantation of ureters	Elective	3
Pyeloplasty	Elective	5
Hirschsprung's	Urgent	10/12
Congenital syndrome (cardiac and skeletal anomalies)	Elective	1.5
Supra-pubic catheter insertion	Elective	4
Interviews 33 - 39 (excl. 34, 35, 37)		
Pyeloplasty	Elective	1.5
Appendicectomy	Urgent	7
Hirschsprung's	Elective	9/12
Re-implantation of ureters	Elective	2
Interviews 41 - 45		
Laporotomy	Elective	5
Renal stones	Urgent	5
Hypospadias	Elective	3
Appendicectomy	Urgent	9
Re-implantation of ureters	Elective	2
Interviews 46 - 50		
Hypospadias	Elective	2.5
Revision of Ventricular shunt	Elective	1
Re-implantation of ureters	Elective	11
Appendicectomy	Urgent	3
Intussusception	Urgent	1.6

APPENDIX 4

Demographic characteristics of parents in the sample

Parents' Characteris tics

Age Group	Mother's occupation	Father's occupation
3/3	Self Employed Chiropodist	Self Employed Chiropodist
2/2*	Part-time Bar	Welder
4/5	Home-maker	Unemployed Roofer
6/6	Home-maker	Railway contract controller
4/4	Part-time Administrator	Teacher
3/4	Home-maker	Joiner
3/3	Home-maker	Clerical Officer
4/5	Home-maker	Product design Engineer
2/4	Part- time Social Worker	Heavy Goods Vehicle Driver
3/4	Home-maker	Miner
3/4	Home-maker	Bricklayer
6/5	Market trader	Accountant
2/3	Home-maker	Ground-worker
5/6	Part-time Dance Teacher	Lecturer
5/5	Self Employed Vidoegraphic	Self Employed Vidoegraphic
5/5	Nursing Auxiliary	Enrolled Nurse
2/3	Care Assistant	Bus driver
5/5	Home-maker	Plumber
4/4	Home-maker	Farmer
3/3	Home-maker	Steel-worker
5/5	Finishing Cook	Printer
3/3	Shop Worker	Unemployed Roofer
4/2	Home-maker	Trainee Mechanic
3/4	Home-maker	Transport Manager

Age group key (* indicates an estimate)

1	>20
2	20>25
3	25>30
4	30>35
5	35>40
6	40+

APPENDIX 5

Guidelines for interviews

Interview number ...

Diagnosis of child:

Occupations of parents:

Mother:

Father:

Ages of parents:

Mother: >20 20>25 25>30 30>35 35>40 40+

Father: >20 20>25 25>30 30>35 35>40 40+

Ages of children in family:

1.

2.

3.

4.

5.

Number of previous occasions this child has been admitted to hospital:

Number of previous occasions other children in the family have been admitted to hospital:

Brief history of admission:

Date of admission:
Date of discharge:

Interview schedule version 2. November 1991. Peter Callery.

What meaning did hospital have for the parent?

- -related to childhood
- -unrelated to this admission

Expectations of involvement prior to admission

To what extent was uncertainty a feature of the experience?

- -was their role/involvement discussed with nurses
- -how did they discover the rules
- -how did the parent know whether they were doing the right things
- -was communication direct or indirect
- -what meaning did they attach to the behaviour of nurses
- -what meaning did they attach to the behaviour of other parents

What were the parent's reasons for wanting to be involved/or not?

- -relative priority of physical and emotional work
- -meaning of parenting to the parent
- -to what degree was the parent reassured by involvement
- -how did the nursing view of parenting match the parent's view
- -special knowledge?

Was there a choice about whether to be involved?

- -painful procedures
- -fear of harming the child

What are the criteria that the parent judges the outcome against?

- -child's emotional response
- -own emotional response
- -child's attitude to a future admission
- -parent's attitude to a future admission

What does the parent feel are the advantages and disadvantages of participation in care?

How would the parent behave differently during another admission?

Guidelines for interviews with parents, March 1992.

This is a draft set of guidelines which indicates the topics which it is expected will be covered in interviews. The guidelines will be modified in the light of further piloting.

Demographic information

Details of the occupations of the parents, the ages of their children and number of previous admissions will be obtained.

Expectations and pre-admission

Previous experiences of hospital
- -self
- -children

Expectations of involvement prior to admission
What would have helped to prepare?
What would you do another time?

Purpose of participation

How did the parent come to be involved?
What do they see as their reasons for being involved?
- -relative priority of physical and emotional work
- -view of what being a parent means
- -for whose reassurance was the parent involved?
- -was the purpose the same as that of the professionals?
- -how did the parent feel about their involvement, what were the advantages and disadvantages?

Process of participation

Role and involvement discussed?
- -on admission
- -at other times

How did the parent find out what was expected of them?
- -how did they know when they were doing the right things
- -direct and indirect communication
- -behaviour of professionals
- -behaviour of other parents

What were the most rewarding and the most difficult/distressing aspects of involvement?

How did they manage the experience?
- shared between family members (what support was available)
- other commitments (work, family)

Guidelines for interviews with parents, continued.

Problems/difficulties

To what extent did parents feel they could choose?
- level, nature of involvement
- painful procedures
- fear of harming the child
- other parents

Parenting on display
- feeling judged
- appropriateness of behaviour

Outcomes

Criteria by which experience judged
- child's reaction
- parent's reaction
- future admissions

Interview schedule: interviews with professionals, March 1992.

Policy towards participation

Encouraged?

What do they see as the reasons for parental involvement?
- quality of care
- staffing levels
- relative priority of physical and emotional work
- view of what being a parent means
- for whose reassurance was the parent involved?
- was the purpose the same as that of the parents
- what are the advantages and disadvantages of parental involvement

When would parents not be involved?

Process of participation

Role and involvement discussed?
- on admission
- at other times
- how do they know what the parents want
- direct and indirect communication
- behaviour of parents
- behaviour of other parents

How does the parent find out what is expected of them?
- behaviour of professionals

Problems/difficulties

To what extent can parents choose?
- level, nature of involvement
- painful procedures
- fear of harming the child
- other parents

Parenting on display
- feeling judged
- appropriateness of behaviour
- responses to inappropriate parenting

Outcomes

Criteria by which experience judged
- child's reaction
- parent's reaction
- future admissions

Guidelines for interviews with parents, November 1992.

Expectations and pre-admission

Previous experiences of hospital
- self
- children

Expectations of involvement prior to admission
What would you do another time?

Purpose of participation

How did the parent come to be involved?
What do they see as their reasons for being involved?
- physical and emotional work
- parental responsibility?
- for whose reassurance was the parent involved?
- how did the parent feel about their involvement, what were the advantages and disadvantages?

Process of participation

How did the parent find out what was expected of them?
- how did they know when they were doing the right things
- direct and indirect communication
- behaviour of professionals
- behaviour of other parents

What were the most rewarding and the most difficult/distressing aspects of involvement?

How did they manage the experience?
- shared between family members (what support was available)
- other commitments (work, family)

Problems/difficulties

To what extent did parents feel they could choose?
- level, nature of involvement
- painful procedures
- fear of harming the child
- other parents

Parenting on display
- feeling judged
- appropriateness of behaviour

Outcomes

Criteria by which experience judged
- child's reaction
- parent's reaction
- future admissions

Interview schedule: interviews with professionals, November 1992.

Policy towards participation

Encouraged?

What do they see as the reasons for parental involvement?

- -staffing levels
- -preparation for discharge
- -relative priority of physical and emotional work
- -for whose reassurance was the parent involved?
- -what are the advantages and disadvantages of parental involvement

When would parents not be involved?
Preparation for discharge

Process of participation

Role and involvement discussed?

- -how do they know what the parents want
- -direct and indirect communication
- -behaviour of parents
- -behaviour of other parents

How does the parent find out what is expected of them?

- -behaviour of professionals

Assessment of parents

- -during admission
- -prior to discharge
- -assessment of relationships

Teaching parents skills

- -feel they've been trained for this?
- -parents upset by procedures?

Problems/difficulties

To what extent can parents choose?

- -level, nature of involvement
- -painful procedures
- -fear of harming the child
- -other parents

Ward rules

- -kitchens, drinks
- -allocation of rooms

Parenting on display

- -feeling judged
- -appropriateness of behaviour
- -responses to inappropriate parenting
- -difficult parents, "intelligence" "sensible parents"
- -the time taken up by parents

Guidelines for interviews with parents, February 1993.

Expectations and pre-admission

Previous experiences of hospital
- self, children

Expectations of involvement prior to admission

Purpose of participation

How did the parent come to be involved?
What do they see as their reasons for being involved?
- physical and emotional work, ?baby model of care
- parental responsibility?
- reassurance:child/self/others at home?
- how did the parent feel about their involvement, what were the advantages and disadvantages?

Process of participation

Structural factors
- canteen, location, cost
- drinks and breaks
- bathrooms and toilets
- beds

How did the parent find out what was expected of them?
- direct and indirect communication
- particular nurses
- professionals and other parents
- parental knowledge and professional knowledge eg pain

How did they manage the experience?
- shared between family members (what support was available
- other commitments (work, family) financial, other costs

Who is "the patient", what is the job of the nurses?

Problems/difficulties

Involvement in distressing procedures:
- nature of involvement, how did it happen
- being firm

Parenting on display
- feeling judged?

Care at home

Preparation for discharge

Care at home
- -difficulties
- -support available
- -who to contact?
- -costs of caring for child at home, eg time off work

Post-discharge behaviour of child, siblings