

**INFORMED CONSENT:
PROBLEMS OF PARENTAL CONSENT TO PAEDIATRIC CARDIAC SURGERY**

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ABSTRACT

Informed consent: problems of parental consent to paediatric cardiac surgery.

This thesis reviews the development over the last 40 years of medical, legal, ethical and psychological concepts of informed consent and then evaluates the abstract theories in relation to the practice of achieving consent to paediatric cardiac surgery.

For two years I observed the work of two paediatric cardiology units in the clinics, wards and staff meetings, and interviewed families and staff. Paediatric cardiac surgery is not a typical kind of surgery, involving as it does proxy agreement to very high risk operations. Yet these characteristics help to illuminate the whole process of achieving informed consent since, because of them, decision making tends to be drawn out. Extended discussion reveals the dependent position of patients, the limits to medical knowledge and skill in a developing specialty, and the kinds of information concerning surgery which are exchanged between families and hospital staff.

The experience of consent has two main elements: to be rationally informed and to feel in voluntary agreement. In order to explore the duality of this thinking, feeling experience which involves doubt and trust, it is necessary to develop a sociological means of taking into account feeling and relationships. Concepts of informed consent which concentrate on reason and exclude feeling are inadequate. These inadequacies are seen more clearly when sociology attempts to overcome the split between reason and emotion and to see how they relate. The different perspectives, knowledge and values of doctors and of families and how these affect the consent process then become apparent.

Influences on the consent process are shown at three levels: the way medical care is organised; the form and content of the information exchanged; and the relationships between the children, parents and staff. Clarifying some of the problems encountered by families and doctors may help them to approach more nearly to the impossible yet important ideal of informed and voluntary consent.

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Attached:

What the parents think.

Survey of the views of parents in the two units 1986

Nursing satisfaction study

Survey of the views of paediatric nurses 1986

Care of children who have died at the Brompton Hospital
and care of their families

Survey of the views of bereaved parents and of the
paediatric nurses 1986

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Needless to say, the responsibility for what I have written remains my own.

CHAPTER ONE

INTRODUCTION

'In our acceptance of medical practice we have accorded doctors the right to inflict pain. Our concern, therefore, has to be to see that [] health workers do not inflict pain unnecessarily; we believe our skills as social scientists make it possible for us to point out the unintended suffering inflicted, suffering which is unrecognised and which may perhaps be unnecessary or avoidable. Our claim [] is to be able to observe and analyse such sufferings in dimensions where doctors and nurses are unsighted by virtue of their training. Their gaze is directed to the mysteries of physiology and anatomy []. Our gaze has been trained to look at the workings of the mind and of society [] to look below the surface of the commonsensical and see the deeper implications.' (Stacey 1979:186-7)

A gateway

In recent years there has been much public interest in matters such as heart transplantation, drug trials, the prescription of contraceptives for minors, and the medical investigation and management of cases of child abuse. These matters all raise questions about the consent of the patient, and in some cases of the parents, to medical interventions, and about the harm or benefit of the interventions. Beyond the personal dilemmas for the individuals involved are questions about relations between the medical profession and society, and between the validity of medical knowledge and of patients' and parents' knowledge. How much licence do we allow to doctors to decide and act on what they believe to be the best interests of their patient or of society generally? Informed consent may be seen as a gateway, opening or closing medical access to freedom of decision, and so regulating the pace of advance in medical knowledge, technique and authority, advance which may be gained through harming as well as benefitting patients.

Informed consent is therefore a vitally important issue for individuals and for society. This thesis aims to explain the current practice of informed, proxy consent to medical treatment for minors, and to question how far parents can or should be informed and involved in decisions about their child's heart surgery.

A paradox

Informed consent to medical treatment is a recent and developing concept, open to many interpretations. It presents problems in its nature and purpose, in its practical achievement and assessment. Philosophers discuss consent as a set of abstract principles. Lawyers use consent as a practical means to defend doctors against litigation, and patients against abuse. Doctors vary from considering consent to be a part of excellent and courteous medical practice, to dismissing it as an unnecessary and empty formality, or an impossible ideal. Psychologists measure evidence of the comprehension and satisfaction of informed patients with very variable results. Some parents see proxy consent as a right, or as a painful or bewildering duty, some see it as a means of supporting, or else of attempting to challenge, medical decisions.

Informed consent, as Kaufman has shown (1983:1659), is a hybrid, spawned from medicine, law and philosophy, 'three disciplines which often oppose one another in basic orientations and interests', and also from a confusion between laws of assault and of negligence. Informed and voluntary consent is an ideal which can be so difficult to achieve that it works in tension with everyday experience. It is a symbol used, especially in North America, by patients, doctors, lawyers and ethicists to protect certain interests, (personal, professional or economic), and to contest other interests, sometimes in ways which bring the concept into disrepute.

Consent is a paradox. Only attained through patients' autonomous judgement, it is a deliberate decision to suspend autonomy, to reserve judgement, and freely to submit to unfreedom and helpless dependence. Information is acquired through questioning and critical assessment, yet this rational process contradicts the voluntary element of consent: willing suspension of disbelief into feelings of trust and hope. Emotions such as guilt, love and fear can confuse, yet also enrich, patients' rational awareness. So in consent, reason and feeling complement yet conflict with one another. It is a process yet also a conclusion, (a form is signed) although for many people the struggle between doubt and trust continues after surgery.

Consent is an activity yet it mainly consists in private thinking. Sometimes it is a difficult struggle but it usually leads to passive acceptance. It is a private state of mind but also a formal public declaration.

Theory and practice

Sociology can perceive the paradox of consent within a broad perspective because it can review the range of both abstract theories and actual practices concerning informed consent, in their historical and social setting. In this thesis, theories of informed consent are summarised into an interpretation of consent as a precaution against suffering. Suffering is defined as physical and mental distress which may be associated with the patient's condition, the medical treatment, or the means and hospital routines through which treatment is provided. Informed consent is reviewed for its capacity to protect children, and for the freedom or constraints within which parents are able to do this through the way they give consent.

Evidence of the practice of consent is based mainly on observations in two paediatric cardiology units. Although these are not claimed to be representative of patients' experience generally, the observations highlight crucial concerns about informed consent which may be taken for granted, or hurried over in low-risk, routine treatment. These concerns become apparent in children's heart surgery, for the following reasons. Many operations carried considerable mortality and morbidity risks with the accompanying risk of litigation, so that careful explanation to parents was seen as very important. The operations were often complicated to explain in lay terms and therefore could involve long, detailed discussions about the nature of treatment, and harm and benefit. Some parents said that they thought and talked about the implications of surgery more deeply when giving consent on behalf of their child, than if they were consenting to surgery on their own behalf, so proxy consent often clearly illustrated problems of direct consent and extra problems as well. Both cardiac units were in post-graduate teaching hospitals in which many of the staff were learning and teaching about talking with families. Patients were treated by

several medical teams not by single practitioners. For all these reasons the processes of informing, discussing, deciding and consenting were often readily observable, being formal and protracted, and allowing parents and staff time to reflect on the whole consent process.

Levels of experience

Sociology's potential for considering several levels of experience is particularly helpful when examining informed consent, a subjective state interacting with external influences. Consent is an elusive subject for empirical research, because much of the process is not easily observed. One way to observe consent is to see it as a complex process which needs to be understood within its social context. The doctors' view of consent is like a set of still photographs: encounters at the clinic, at admission, when signing the form. Yet the parents' experience is like a continuous film. Parents digest information between medical encounters, discuss and add to it with a range of people, change as their knowledge increases, and continue to learn until well after the operation. Sociological research can observe only brief episodes in a process which could last for months. Parents' experience of the consent process is often ambiguous, changing and uncertain. Research which measures, say, parents' comprehension or satisfaction at a certain stage can only assess a transient, partially conscious state, seldom a definitive or permanent one. This is because the child's condition may frequently change and may be explained with different shades of meaning by changing rotas of staff. It is also because consent involves many partly understood feelings. The paradoxical nature of informed consent complicates attempts to research it. Empirical studies which assume that consent is simply a rational process, or a single unchanging response, or a clearly demonstrable, measurable reality miss key elements of consent.

Other difficult aspects to observe are partly invisible elements such as respect, duress, or voluntariness. Respect or duress may originate from external forces or may be sensed or imagined by the patient. Despite its obscure nature, duress is a

central concern in voluntary consent (Nuremberg Code 1947) because, apart from knowledge of what is being consented to, the other essential condition for adequate consent is power freely to agree or to refuse. This freedom is only possible within reasonably equal relationships free from duress. Part of duress can be the compulsion to appear to be willingly compliant. Patients' consenting words and behaviour may have no relation to their willingness to receive treatment. There are therefore problems for empirical studies which attempt to measure the quality of informed consent in, say, patients' expressed satisfaction, since these can measure only words and not mental states. The studies may themselves become part of the constraints making patients feel obliged to simulate satisfaction. Means of addressing these problems through research which aims to trace connections in a process rather than to measure practices and which aims at equality between researcher and researched are discussed later. They are mentioned here to indicate why I have attempted to take into account the following levels of experience.

There are 'macro' influences which include the social beliefs and practices surrounding surgery, the structure of national health service tertiary care and of hospital administration, relations between the professional hierarchies, public and media attitudes towards heart surgery, and other political and economic influences on the adults agreeing to the child's treatment. These can have enabling and constraining effects on the quality of consent.

There is the 'micro' level of interaction between individual staff and families and the children's different social and medical experience. Here the major influence on decisions about surgery would at first seem to be the child's medical condition. However the central factor may be social not physical, human responses to physical realities based on perceptions of the child's interests. Choice is not always starkly between life and death but between relative harm and benefit, such as deciding when the quality of a child's life is so poor that very high risk surgery is a reasonable option.

Innovations such as heart transplantation offer new choices.

Even if eligible patients reject transplant surgery, they still cannot avoid the dilemmas, responsibilities, and potential for benefit or regret, which new technology can create. Macro and micro levels cannot clearly be separated. Patients are subject to ideological pressure when the mass media raise new expectations or portray heart transplant patients as heroes and the transplant as wholly beneficial. Notions of harm, benefit, interests and rights can change fashion, so that informed consent needs to be reviewed in the context of prevailing social values.

Another level, which interacts with the first two so that distinguishing between all three is only an analytical exercise, is the patient's response to outer influences. This includes personal perceptions of risk and benefit, of medical information and relations with the staff. Patients may sense powerful influences which doctors are not aware of, or do not intend to exert, or are not exerting, influences such as medical optimism or pessimism about the prognosis, or seeming impatience with the patient's questions. Subtle influences, which have strong effects on patients' consent, are difficult to examine through empirical research. The problems for doctors in assessing whether patients are informed and freely consenting are also present in sociological research, with the added problems of ascertaining whether patients as sociology research subjects are cooperating willingly or with reluctant compliance.

Published research on patients' consent tends to isolate single factors such as patients' comprehension or anxiety. This approach seems to go off at a tangent from central questions of voluntary consent: what prompts patients to give consent and what does the experience involve? Yet these questions are perhaps about an invisible, little known, partly subconscious centre which cannot be observed directly and is best understood by looking at a cluster of issues surrounding it. The issues include the quality of medical information and the doctor-patient relationship, the range of choices, patients' comprehension, their sense of risk and of trust, and their freedom to negotiate on reasonably equal terms of knowledge and of status. Each of these issues concerns subjective perceptions and can only partly be observed. Yet by seeing them together, a picture may be

filled out which gives some indication of the experience of consent. My research method has therefore been to try to draw together different levels of experience and different issues surrounding consent.

Connections

The method of drawing issues together becomes possible through theories which make connections and which question conventional divisions of knowledge. Sociology can then be concerned both with observable activity and also with our less visible essential identity, feelings and expectations, with social structures and with individual agents. Making connections enables consideration of patient consent as an activity and as a feeling state.

Traditions in science, medicine, philosophy and social science, influenced by Enlightenment theories, divide reason from feeling, mind from body, objective from subjective, fact from value, and data from interpretation. They also tend to separate the following pairs: abstract theory and contingent experience; respect and care; questioning and trust; detachment and compassion; hospital and medical practices from their personal effect on families. Pairs are treated as if each half were mutually exclusive. In the following chapters, these dichotomies are questioned, showing how they create problems for patients and how, in order to understand and practise the dual nature of informed and voluntary consent, we need to see the connections between the supposed opposites.

Benefit and harm

Paediatric cardiology brings immeasurable benefits to children and their families. Many parents gratefully praised the skill and kindness of the hospital staff. This thesis does not give a fair picture of the benefits and success of the cardiac units; these are some of the reasons for this omission and for the attention given through the thesis to harm and distress. Firstly, my subject is not the excellence of the medical, surgical, nursing and paramedical care but a small and very difficult aspect of this care, the process of informed consent. Secondly, there were certain routines, and severe constraints of time and resources, which adversely affected both

families and staff. Within these constraints, individual staff provided very high standards of care. The problems to be discussed often arose because of medical and hospital organisation rather than individuals' actions. By showing some of the constraints and their effects in impeding informed consent I hoped to suggest ways of easing problems and improving conditions.

Thirdly, families were observed and interviewed during the crisis of surgery when parents tended to be conscious of present risks rather than of future benefits. Their distress was largely due to the problems of the child's condition which the units aimed to alleviate. Yet the ends of health are sometimes pursued through distressing means in the treatment and the hospital organisation. 'We parents look all right but underneath we are in agony,' said one mother. Another said, 'You see people who just cannot cope but there is no one to help them.' Distress is a central issue in consent in signifying how and why consent is given and what painful procedures it permits.

Fourthly, rapid medical and technological advances can leave behind social and psychological knowledge and support, thus reducing our capacity to cope with the benign and harmful effects of science. Informed consent is one means of trying to preserve a balance between the interests of science and of care, between innovation and safety. Efforts to ensure that patients understand and agree to treatment can act as a way of regulating scientific advances to a rate which society can accept and which prevents suffering. As a connecting point between scientific and humane considerations, consent illustrates tensions between them. In centres of medical discovery and research, such as the two cardiac units, the tensions between science and care become more obvious and the achievement of informed consent more difficult.

Finally, I have not attempted to give a representative picture of all the grateful families who, like Tolstoy's happy families, 'are more or less like one another'. Because each unhappy experience or family 'is unhappy in its own particular way' their variety takes longer to describe and offers a clearer understanding of the nature of consent than does the similarity of success.

DEFINING TERMS

Words in the thesis title are open to various definitions, so the meanings used in this thesis are summarised here.

Informed consent is taken to mean the whole process of being informed and moving towards voluntary agreement about treatment. Consent is also used as a shorthand term for this often lengthy process.

Parents denotes parents or guardians, the adults legally permitted to give proxy consent for each child. Consent was given for children in care sometimes by social services, or by the natural parents even if, as in one case observed, they had not been in contact with the child or her foster parents for many years. 'Parents' and 'patients' are used interchangeably when the proxy shares experiences similar to those an adult patient would have when considering consent.

Children are patients aged from birth to 15 years, as 16 is the usual age at which proxy consent is no longer legally required for surgery. The large and very important subject of consent of adolescent patients is only briefly discussed in this thesis.

Varying definitions of paediatric cardiology are discussed in chapter 5.

Surgery is taken to be a set of hospital practices essential to surgery involving admission, investigations and postoperative intensive care. Innovative surgery is very broadly defined as high risk techniques of surgical and postoperative intensive care of which the longterm physical and mental effects are as yet unknown.

Anonymity All the children's names have been changed. Adults are usually described by their relation to the child, such as mother or doctor.

In quotations ... means long pause; - means short pause;

[] means words omitted.

CHAPTER TWO
VOLUNTARY AND INFORMED CONSENT

'1. The voluntary consent of the human subject is absolutely essential. [] To be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion.' (Nuremburg Code 1947)

The purpose of this chapter is to see the ways in which present, widely accepted theories contribute towards or restrict knowledge of patient consent. Literature on consent is analysed to show the contradictory and dual nature of informed and voluntary consent and the difficulties in attempting to achieve it. Concepts of patient consent developed in medicine, the law, philosophy and psychology are reviewed, followed by sociological theories relating to the study of consent. Further theories will be discussed in later chapters as they arise in relation to the research material. The theories are very fully explained and debated in numerous publications and so are only briefly evaluated here.

Medical concepts of patient consent

The concept of consent is based on respecting the person as an autonomous individual. Theories about individuality and personal and civil rights emerged towards the end of the Middle Ages. They were refined by Locke in the 1680s, by Kant a century later, and were declared in the American Bill of Rights in 1776 and the French Declaration of the Rights of Man in 1789. The American Medical Association's first Code of Medical Ethics, 1847, was mainly concerned with medical interests and etiquette rather than the ethics of respecting patients' autonomy. Informed consent to medical interventions is a recent concept. As late as 1946, an American trial for TB treatment, used as a model for modern therapeutic controlled trials, was conducted without patient consent.

Medical codes, oaths and declarations are short statements about prescribed standards of practice. Modern codes are agreed by national and international medical organisations. Significantly, the only formal medical codes which refer to

patient consent are concerned with medical research. None of the codes on medical treatment refers to informed consent, they mention only respect for life and protection of the patient from harm, for example, the Hippocratic oath, International code of medical ethics of World Medical Association, 1949, 1968, 1983, Declaration of Geneva of World Medical Association 1948, 1968, 1983, Declaration of Oslo 1970, of Sidney 1968, of Tokyo 1975. (Copies in Phillips & Dawson 1985)

The first modern codes on medical research were drawn up by doctors in response to public outrage, at 'over-research', such as the Nazi medical atrocities, (Nuremberg 1947), and at under-research such as the thalidomide cases, (Report of the Medical Research Council 1962-3, Declaration of Helsinki 1964). Doctors like Beecher (1970), have been among those who alerted public attention to the abuse of medical research subjects and who campaigned for reforms. Medical codes may be regarded partly as a publicity exercise in apparently tightening medical control over the profession in order to forestall intrusion from lawyers and politicians. The dangers of many medical procedures become more obvious when the hope of benefit associated with therapy is absent. Doctors are then vulnerable to criticism and they respond by drawing up codes about informed consent of research subjects.

Informed consent of clinical research subjects requires six elements: information about the purpose, nature, substantial risks, potential benefits of the intervention, about alternative treatments, and about the subject's right to withdraw at any time without prejudice to further treatment. (Nicholson 1986:242) These elements of consent are only slowly and loosely being applied in clinical care of patients, partly for fear that patients will harm themselves by refusing benefits of treatment, a risk not present in research devoid of therapy. Debate about consent is complicated by uncertainty about, for example, how 'substantial' or likely to occur the risks should be before patients need be informed about them. There is also uncertainty about the competence of some patients to give consent. Patients usually depend on the doctors' subjective assessment of 'adequate' medical information and of patient competence.

Benson et al (1985:1331) identify five major aspects of consent (to psychiatric treatment), the patient's ability: to give free voluntary consent; to have all the relevant information; to be competent to give consent; to understand the information; to make a decision which the doctor will respect.

The first formal definition of consent to medical procedures, the Nuremburg Code (1947), begins with the statement about voluntariness quoted at the head of the chapter. Voluntariness is set before information. This important emphasis is lost in later codes, which stress information, as if assuming that as long as subjects have been given facts and in return have stated or implied their agreement there are no problems. This assumption overlooks personal issues, such as the quality of the relationship between doctors and those they treat, the discrepancy of power and freedom of choice, and complexities of consent such as duress, which describe affective aspects of relationships and intentions that cannot be reduced entirely to matters of logical reasoning.

On information, the Nuremburg code states that the subject:

'should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.'

This apparently allows for elements other than purely scientific ones to influence decisions, such as personal and ethical criteria in which the patient may be the most knowledgeable.

By 1975, with the Declaration of Helsinki, the language, tone and meaning have completely changed. Here the first point is:

'1. Biomedical research involving human subjects must conform to generally accepted scientific principles and should be based on adequately performed laboratory and animal experimentation and on a thorough knowledge of the scientific literature.'

In technical, instrumental language, the code prescribes an efficient contract to achieve a scientific objective which is not expected to have personal or affective elements. 'Scientific principles and literature' in which only the doctors are expert determine practice not, for example, ethical principles or human responses.

The earlier concern for personal as well as scientific values shows in a second difference between the codes. Nuremburg emphasises voluntariness, related to the will and to emotions within human relationships such as hope, courage, trust, fear or coercion. This is in marked contrast to Helsinki's avoidance of feeling and concentration on reason, only once alluding to 'the subject's freely-given, informed consent'. Information, assumed to be the rational component of consent, is more easily standardised and controlled within the province and skill of scientific experts. At present, information and not voluntariness is the main interest of research and comment about informed consent in medicine, the law, philosophy and the human sciences. The impersonal emphasis in current western medical practice, which can work against the interests of patients, is thus reaffirmed rather than challenged in the current codes.

Legal doctrines of informed consent

Traditionally, the consent of the patient has been the factor distinguishing surgery from assault, although until recently, western legal systems paid little attention to the quality of consent. When cases came to court, the law tended to support the surgeon who claimed that consent had been implied. Kaufmann (1983) summarised the Anglo-American legal origins of consent:

'While absence of consent constituted an action of assault and battery, failure to inform the patient constituted negligence. Informed consent is a hybrid legal concept spawned from the union between the legal concepts of battery, and negligence in medical malpractice litigation. The concept was born out of a confusion between two distinct branches of tort law.' (p1660)

Whereas medicine is guided by assumptions of professional autonomy and benign paternalism, Anglo-Saxon law is founded on notions of individual autonomy. (Katz 1976) Gradually the courts have come to defend the patient's rather than the doctor's right to autonomous decision, particularly in America. In 1960, a Kansas court found a doctor guilty of negligence because, although the treatment was skilful, he had failed to provide reasonable information to the patient about risks. (Natanson v. Kline)

American law defines 'reasonable' information as what a reasonable patient would want to know.

'Respect for the patient's right of self-determination on a particular therapy demands a standard set by law for a physician rather than one which the physicians may or may not impose on themselves.' (Canterbury v. Spence 1972)

American law also holds the doctor responsible for seeing that the patient is informed, as does Canadian law, in this example:

'In obtaining the consent of a patient for the performance on him of a specific operation, a surgeon, generally, should answer any specific questions posed by the patient as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation.' (C Laskin in Hopp v. Lepp 1980)

British law, however, defines 'reasonable' information as what a reasonable doctor would decide to tell. (Bolam v. Friern Hospital Management Committee, 1957)

'What information should be disclosed, and how and when, [is] very much a matter for professional judgement in the context of the doctor's relationship with a particular patient in particular circumstances.' (M Donaldson in Sidaway v. Governors of the Royal Bethlam Hospital and others, 1984)

Yet British doctors and the public are increasingly influenced by American concepts of informed consent. American lawyers have constructed increasingly elaborate contracts for the doctors and hospitals, or the patients who employ them. The influence of consumer movements, demanding freedom of choice and information about services, parallel these legal developments, and are perhaps stronger in the United States where medical care is directly paid for and regarded as a consumer commodity. The British NHS appears to conserve greater inequality between expert professionals and dependent patients. American and Australian Patients' Associations, for example, publish Patients' Bills of Rights which have no parallel in Britain.

Some British lawyers are interested in defining the nature of reasonably informed consent, saying that this matters too much concerns the public interest to be left to doctors. (Kennedy 1981)

Other lawyers are more protective of medical interests. In the Sidaway case 1984 quoted above, the judge ruled that a woman severely disabled by neuro-surgery had no grounds for complaint that she was not warned of the risk of injury because the doctrine of informed consent was 'no part of English law' since most patients 'preferred to put themselves unreservedly in the hands of their doctors'. (British Medical Journal, 1984 288.802-3) However, opinions are slowly changing and Lord Scarman (1986) warned a medical meeting that unless the profession 'put its house in order' and ensured that patients were reasonably informed of risks of treatment, doctors may have reforms forced upon them through the courts.

The American legal doctrines of informed consent do allow for therapeutic privilege which allows doctors to withhold information if this is judged to be in the patient's interest or if the patient does not wish to be informed. In 1987, the English High Court found two health authorities negligent for failing to warn patients sufficiently of the risks of treatment although both decisions were reversed by the Court of Appeal. (Blyth v. Bloomsbury H.A. and Gold v. Haringey H.A.) British courts at present accept medical advice that it is 'reasonable' to withhold information about risks which might distress patients. In one case it was judged reasonable not to have warned a patient, who later became pregnant, that her sterilisation might not prove wholly effective. Slowly medical opinion is changing, partly owing to legal pressures, as more doctors believe that it is reasonable to inform about risks. (Dyer 1987) Yet the threat of adversarial litigation can also have the opposite effect of eroding trust and care, the bases of open relationships between doctors and patients.

Children and the law

The 1969 Family Law Reform Act states that:

'The consent of a minor who has attained the age of 16 to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be

necessary to obtain any consent for it from his parents or guardian.' (s.8)

Traditionally the law sees parents/guardians as defenders of the child's interests and requires their proxy consent to medical procedures on children under 16 except possibly in emergencies or if the child has clearly left the family. The interpretation of this law is complicated, for example, by common law which holds that the 'age of discretion' is 16 for girls and 14 for boys. The complications of consent to nontherapeutic medical interventions on children are discussed in Nicholson. (1986:125-139)

Recent controversies have drawn attention to confusions in legal and public thinking about children's rights, competence and interests. The case of *Gillick v. West Norfolk AHA* (1985) concerns parents' rights to control consent to their child's medical treatment (in this case contraception) as against the older child's rights to privacy and choice. There is a basic conflict in the law between the needs and rights of children for nurturance yet also for self-determination. One anomaly arising from rulings that a child's consent to her own medical treatment is not accepted in law, is that a 15 year old mother must give or withhold consent to surgery for her baby but not for herself. (Lancet 1985,1(8424)342) The debate about children's competence asks whether there should be a minimum legal age of consent or if 'the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.' (Scarman, House of Lords decision on *Gillick* case 1986) The latter understanding raises problems about who can determine the child's competence and the risks of removing vulnerable children from the protection of proxy consent.

Parents' authority, prudence and ability to protect their child's interests has been questioned. Children of Jehovah's Witnesses are made wards of court in order that they may receive life-saving blood transfusions. In 1981 Alexandra, a Down's baby, was made a ward of court so that she might have urgent abdominal surgery after her parents had withheld consent

believing that her early death was in her best interests. Also in 1981 was the trial of Dr Arthur, a paediatrician who followed the request of parents of another Down's baby to 'help him to die'. Both cases raised questions about the wisdom and justice of decisions made by parents and doctors on the child's behalf. This year, legal proceedings about child abuse cases have intensified these questions. The cases also highlight the damage that can be done to children when the State intervenes in the family, and the State's inability to ensure adequate alternative care in children's wards or Homes when children are removed from their parents' control.

Older legal views are based on parents' property rights over their children, and on respect for the autonomy of the family and the authority of its head. These views are changing into the belief that parents have duties to safeguard and care for their child. Parents have rights only in so far as these enable them to fulfil their duties. Yet the law seems to be advancing in contradictory directions. The Children's Legal Centre, the European Court of Human Rights and other bodies are achieving new rulings to protect children from physical and mental abuse. New (and controversial) ways such as video recordings are used to listen to young children and to allow their voice to be heard in the courts. Parents' powers of control are being restricted and taken over by the State. Yet at the same time new powers are being given to parents which were previously withheld, such as the right to have their mentally handicapped daughter sterilised, even if she is an adult.

The present contribution of the law to understanding consent to high risk surgery for children lies in the way the law uncovers and explores central dilemmas of children's interests and rights, rather than in arriving at any clear solutions. There is increasing legal regard for the child's interests as perceived by the child, thus slightly reducing reliance on adult assumptions about children's best interests. There is also growing interest in the assent to research (not actually refusing interventions) of children over six years, (US President's Commission 1982; Nicholson 1986) and in the child's consent (informed and voluntary agreement) to research and treatment from

the age of 13 or 14 upwards (Rayner 1987), although the child's competence rather than age should influence assessments of the child's ability.

Connections between therapy and research

Medical codes and legal analyses tend to suggest a generality and clarity not always found in clinical practice. The distinction between research and therapy is often not clear, much treatment being partly experimental and much research partly therapeutic. Modern medicine involves difficult compromises: between deciding when there is sufficient knowledge about new therapies to risk using them or to hold back cautiously and yet watch patients suffer who might otherwise benefit; between telling patients truthfully about risks of treatment yet harming patients by raising much anxiety.

The struggle, to maintain a controlled balance between harm and benefit and between individual and collective interests of patients, is particularly complicated in paediatric cardiology. About 20 years ago, cardiologists working on middle-aged, acquired heart disease had little interest in the totally different congenital heart defects of children. Today, almost all these defects can be alleviated or cured. Yet steps forward can have a high price. Medical lectures are illustrated by slides of graphs showing the 'learning curve'; mortality rates for a new operation fall sometimes from about 100% down to 50% then 15% over a few years as the whole cardiac team improve their knowledge and skill, discover new techniques, and learn from mistakes. One intensive care sister told me:

'The difficulty of the work hasn't changed much over the years. The cases that we used to think were so difficult are easy now. But we are treating more and more complicated new cases who would have died a few years ago.'

During my two years in the units, certain operations came to be thought to be safer, while long-term adverse effects began to be apparent for others. Doctors spoke of their work as experimental, 'no one knows what the effects will be in 30 years'. Drug trials are carefully regulated, but new surgery techniques need not first be approved by Research Ethics

Committees, or even be explained to patients. The subject is very much more private and literally in the surgeons' hands. After long medical discussion about surgical alternatives, the surgeon may say, 'I will decide when I get in there and see what is going on.' As doctors wryly admit, sometimes only the pathologist can inform them precisely about the heart defects when they have the 'specimen', the dissected heart postmortem. There was a belief that all accepted therapies which had not been through controlled trials ought to be tested, and that the discipline of systematic research was a major safeguard of patients' interests. Yet the doctor-patient relationship, when the patient's welfare and comfort is expected to be the first concern, can conflict with the researcher-subject relationship, intended to serve the interests of research, sometimes to the discomfort of patients.

Research and innovation can present problems when negotiating consent, because of limited medical knowledge and prediction before a trial, and moral dilemmas about how freely to admit failures afterwards. For example, at one medical meeting I observed, doctors decided that 13 children who had had a new form of palliative* surgery were beginning to show adverse effects five years later and no more of the new operations should be tried, they should revert to the established method. At another meeting doctors discussed how to identify beforehand the children who will 'succumb' from a particular operation, because, 'if they are going to die anyway there is nothing to lose by trying out the new technique on these ones to see if it might work.' This case raises questions about whether, and how, to say to parents, 'We are almost certain your child will die from this surgery, but she will die anyway and we think it is worth trying something. The new operation might give your child a better chance of survival or it might be even less likely to succeed than the usual method.' There is a growing debate about whether doctors should shield parents from this responsibility and anguish, or whether patients and relatives or the general public, lawyers or the media ought to share in influencing these decisions.

* See appendix of medical terms.

Literature on informed consent - empirical research and medical commentary.

Empirical studies on topics related to informed consent, such as on doctor-patient interaction, patients' comprehension or recall of medical information and their response of anxiety or satisfaction, have arrived at conflicting conclusions. These studies have been made by doctors and, usually under medical auspices, by psychologists, sociologists and nurses. Summarising two decades of research on patient consent, Kaufmann (1983:1662) wrote:

'the dominant paradigms for the medical analysis of patient decision-making favoured physician autonomy and control. The principles of patient self-determination and informed choice found support among only a minority of physicians and researchers. For the most part, medical opinion was guided by the more traditional belief that paternalism was good for the patient, and that legal attempts to reform the physician-patient relationship were unwise and unwarranted. Sound medical judgement, physician autonomy and patient trust were the only valid bases for medical practice.'

In order to summarise briefly the conclusions of many empirical studies, their findings will be broadly divided into their reasons for and against informed consent. Studies referred to are chosen from a much wider selection.

Arguments against informed consent

- 1 Belief that most patients prefer not to be informed of risks (Alfidi 1971, 1975; McIntosh 1977; Fraser 1984; Hoy 1985) and that they prefer paternalist doctors (Le Baron et al 1985).
- 2 Evidence that patients are incapable of understanding medical complexities, (Garnham 1975) and cannot recall medical information (Leeb & Bowers 1976; Cassileth 1980).
- 3 Dismissal of the 'mythical fantasy' of informed consent (Ingelfinger 1972; Leeb & Bowers 1976; Benson et al 1985).
- 4 Concern that legal requirements would seem to express doubt in medical beneficence or competence to decide in the patients' best interests and thus would undermine trust and create 'bad faith' between patients and doctors (Laforet 1976; Brewin 1985).
- 5 Objections that lawyers are unable to clarify guidelines on risk and benefit, or on 'reasonable information' and fear that if

patients were allowed to define 'reasonably informed', doctors could be found guilty of malpractice despite conforming to medically accepted standards; also that the legal doctrine would constitute an assault on the autonomy of the medical profession (Delee 1976).

6 Concern that information can seriously alarm and harm patients, and may cause them to refuse beneficial treatment (Burnham 1966, King 1976, Loftus & Fries 1979; Gert & Culvert 1981; Cairns et al 1985; Taylor & Kelner 1987). Lankton et al (1977) found a mixed response to their study.

7 Evidence that giving full explanations will cause patients to refuse to take part in research (Simes et al 1986) and that having to seek informed consent deters doctors from asking patients to be research subjects (Taylor & Kelner 1987).

Arguments in favour of consent

1 Evidence that most patients want more medical information than doctors provide (Korsch & Negrete 1972; Waitzkin & Stoeckle 1976; Locker & Dunt 1978; Cartwright & Anderson 1981; Faden 1981; Kemp et al 1984; Elian & Dean 1985).

2 Evidence that patients report greater satisfaction when doctors are informative and sympathetic (Koos 1954; Ley 1983; Murphey-Cullen & Larsen 1984), and when doctors discuss patients' concerns (Korsch & Morris 1969; Lardsden & Rootman 1974).

3 Reports that informed patients are more compliant with treatment (President's Commission 1982; Ley 1983).

4 Findings that patients can comprehend and recall medical information especially when given simple, written information to keep (Simes et al 1986).

5 Beliefs that patients have the right to be informed (Bok 1980; Schain 1980; Buchanan 1981), and that doctors have a duty to inform patients even if they then cooperate less in research (Baum 1981).

6 Beliefs that informed patients are less likely to be coerced into experiencing clinical or research interventions which may be of little or no benefit to them (Papworth 1976; Beecher 1970; Harrison 1986; Stinson 1983; Scanlon 1984; Bates & Lapsley 1985).

7 Advice that doctors are protected from litigation when it can

be shown that patients have been reasonably informed (Scarman 1986; Dyer 1987).

8 Evidence with organ and tissue transplants, that informed consent is a necessary safeguard against unethical use of human subjects and a screening device for selecting donors for innovative surgery (Fellner 1970, 1971).

9 Reports that although anxiety levels may rise when patients are informed in detail, they appear to be calmer during and after procedures, to recover physically and psychologically more easily than less informed patients, and to suffer less unnecessary anxiety about imagined problems, (Denney 1976; Rodin 1983; Greenfield 1985; Wallace 1986; Kelly 1987).

It is difficult to discern any clear trend from this range of conflicting evidence and argument. Korhman (1985) suggests a movement over two decades towards greater support for informed consent. This is likely to happen as medical and public expectations and expertise increasingly encourage and realise higher standards of informed consent. The conclusions should be read with caution. Some of the studies are meticulous, in others there is a lack of detail about what patients are told. Concepts such as 'trust', 'anxiety', 'paternalism' are often assumed as clearly defined and agreed, rather than as the subject of uncertainty and disagreement. Conclusions are based variously on real patients at different stages of illness and on hypothetical questions asked of well people. It is seldom clear whether patients' alleged incomprehension is due to their incompetence or to ineffective methods of medical communication. Comprehension and grasp of the main essentials at the time of consent is confused in some studies with the quite different ability to recall and retell information weeks or months later. (As parents told me, some people want and need to forget such traumatic occasions.)

Many of the studies have positivist theoretical bases the limitations of which are considered in the next chapter. There is a tendency to make the following assumptions: doctors initiate interaction and patients only respond; anxiety is a negative state which should be controlled; the consent process is best

understood through scrutiny of small aspects of it taken out of context from the patients' continuing experience; reasoned information is separate from feeling understanding. As a result, informed and voluntary consent as a reasoning and feeling state tends to be fragmented. I will discuss later the importance of seeing consent as a whole process.

Medical ethics

Underlying the practical concerns of doctors and lawyers are concepts of ethical standards. Debates in medical ethics contributed much towards my understanding of events in the heart units and so a few of its main theories have been summarised very briefly here, and some will be developed later. Medical ethics, a recent development in moral philosophy, differs from ethical medicine, an ancient tradition of doctors and patients trying to find the best answers to their dilemmas.

Medical ethics has created, explained and often clarified theories which underlie practical attempts to resolve medical dilemmas. It has also clearly shown the moral threads within the fabric of medical decisions. This has revealed that many medical decisions are neither purely clinical nor need they be the sole prerogative of doctors. The ethical ideal of informed consent, a central theme of medical ethics, has worked as a key symbol to increase awareness of patients' interests and rights.

The mainstream of medical ethics is founded on Enlightenment philosophy, emphasising pure reason, and seeking to clarify ethical dilemmas by logical analysis. The abstract bones of a problem are supposed to be seen more clearly when separated from the flesh of the historical, social and personal context, and when subjected to critical and impartial evaluation. (Hare 1975; Raphael 1981) Ethicists aim to construct a comprehensive, coherent moral theory, based on universal principles applying to all cases (Gillon 1985), although they admit that the structure 'sometimes is not as tidy as we wish'. (Beauchamp & Childress 1983)

Esteem for pure reason values a rationalist conception of the person as a reasoning, autonomous being. This tends towards Cartesian concepts of the self as a disembodied intelligence.

Seeking informed consent is perceived as a necessary form of respect for the autonomy of the rational person.

Ethicists consider that orderly society depends on rules, duties and obligations which people obey through reasoned conviction. Duty is a necessary sanction because disposition (our feelings, desires and needs) is not thought to act as a sanction or to be a source of morality. An example from Beauchamp & Childress illustrates the concern to formulate disorderly experience into neat categories susceptible to logical analysis.

'Beneficence will be treated as a duty, and thus as distinct from mere mercy, kindness and charity. [It] asserts the duty to help others to further their important and legitimate interests [] and requires [] a balancing of benefits and harms (utility)[]. The line between a duty and a moral idea is not always easy to establish, and beneficence has proved to be the most troublesome moral duty to place firmly in one of these two categories. (1983:148-50)

Medical ethics is a rapidly growing and respected specialty. Yet the work of the mainstream writers has been subject to the following criticisms.

If the ethical purpose of informed consent is to observe respect for the patient because he or she is a being capable of pure reason, there is a danger of seeing consent as irrelevant to people incapable of pure reasoning. This includes the very old, young and handicapped, and those considered to be mentally ill, or in too much fear or pain to think clearly - in fact most patients. Eighteenth century concepts of independent autonomy fit uneasily with dependent patients. Kant (1970:139) considered that only a few men (not women, and the lower classes) were fit for independent autonomy and the respect due to it. Mendus (1987) quotes Kant's writing which expresses his deep contempt for the body. This contempt is just one complication of applying his theories to sick patients. MacIntyre (1981) criticises the ahistorical use of philosophical theories from many different centuries and cultures, as anachronistic and confused. Concepts of autonomy can be unhelpful, confusing and can be used to undermine patients' interests. Harris, (1985) and Weir (1984), for example, question the right to life of babies because they

are not reasoning beings. Weir argues that ethical committees, remote from patients, should be used to make impartial decisions since he sees emotional involvement as a handicap to reasoning. Medical ethics has opened medical decision making to lay involvement by identifying latent nonmedical issues. Yet ethicists are trying to create their own arena of unique professional expertise, arguing that rigorous analytical skill is necessary. As Freidson (1970) shows, new professions are partly achieved by creating an ignorant and dependent laity. There is a danger that ethicists, instead of helping to increase patients' share in making decisions, will usurp and exclude them.

The emphasis on pure reason, in separating mind from body, leads towards disregard of physical harm, and so can reduce the value of informed consent as a precaution against suffering. Consent becomes a medical courtesy, an abstract exercise in respect. The importance of proxy consent for young children rises when consent is seen as a defence for very vulnerable patients but falls when consent is seen as respect for rational beings. Typically, medical ethics literature assumes a model of the patient as a middle class competent man, someone most able to command respect and therefore perhaps least in need of protection. The usual model in moral philosophy, of *equal, reciprocal* relationships, ignores concerns which are central to morality. These concerns are: the potential for harm and benefit within *unequal complementary* relationships, such as between doctors and patients; and sensitive attention to individual's differing needs and responses instead of concentrating on general, universal standards. (Gilligan 1982; Benhabib 1985) Dilemmas in medicine arise mainly with the kinds of patients, largely ignored in the 'neutral' style of ethics writers, all those are not able to make clear decisions or to command respect, (Grimshaw 1986) and those adversely affected by social contexts, the 'unsung questions of medical ethics'. (Barnard 1985, Alderson 1987)

Separating 'pure' reason from emotion obscures the importance of emotion although it is central to morality. Benefit and harm can only be understood when their feeling effects of joy, relief, pain, sorrow or fear are acknowledged. Feelings are a source of

moral need and also of moral understanding. (Blum 1980: Gilligan 1982; Seidler 1986) Through our disposition, (our feelings, desires, needs and essential being), we learn how to relate to others with care and justice. Gilligan traces a shift in modern psychology from respecting moral reasoning towards respecting moral emotions, seeing empathy and concern as

'the essence of morality. [] Apart from our relationships there would be no moral necessity so that a perspective on relationships underlies any conception of morality.' (Gilligan & Wiggins 1985:1,4)

Recognition of moral feelings within relationships helps us to see the inadequate morality of the objective detachment valued in medical ethics. This new understanding of moral feeling will be discussed through the thesis.

My consideration of consent in the two cardiac units will be based on the assumption that every relationship is complex and unique. General conclusions may be drawn but without qualification they can be inadequate for resolving immensely varied moral dilemmas. Attempts to see dilemmas more clearly by abstracting the general theme from the contingent circumstances can close our vision to the real significance of the problems - their intense meaning to the individuals concerned. Morality is concerned with conflicting opinions and dynamic struggle towards new understanding and change. Problems of informed consent arise when doctors and patients disagree. Medical ethics tends to convey a sense of morality as one-sided, as correctly defined by medical values. Terms such as 'important' or 'harms' tend to be used as if their meanings are given, static, and not subject to doubt or dispute. It is implied that effort is required simply to think clearly and unemotionally enough in order to see the correct answer. For example, Raphael (1976:8) says that philosophers 'speciality is clear thinking not factual investigation.'

However, Grimshaw (1986:24) asks, 'What clear thinking is it that philosophers are supposed to be especially good at?' She shows that their aim of clarity is mistaken on two counts. 'Discussion of "meanings" or of "concepts" cannot be divorced from consideration of the "facts" to which they apply'. This is

partly because we cannot avoid using concepts and language loaded with personal meanings and values, for example the words 'baby' and 'neonate' have very different implications. Secondly, 'no amount of "mental house cleaning" is going to provide a neutral resolution to questions of power, dependence and competing values.' (ibid:26) Grimshaw says that when elderly male philosophers write about, say, abortion in 'neutral' terms of 'we' and 'our choice', they are writing from their own remote viewpoint. They are not imagining the position of women forced to consider abortion. So the actual compelling reasons and needs surrounding abortion are screened out of the abstract philosophical theories. 'Universal' laws are liable to miss out women's and children's needs. One result can be the danger of seeing women's refusal to consent as irrational, an emotional over-reaction, in contrast to reasoned 'impartial' medical advice. So that ethical arguments elevating pure reason can actually undermine belief in the need or ability of anxious patients to withhold consent.

Giddens (1982:60) argues that the attempt, as in medical ethics, to build 'a prototype for all knowledge creates a masked form of legitimation of structures of domination.' It is deeply authoritarian and covers over problems of unequal power and resources.

A further weakness is that medical ethics is seldom reflexive. Ethicists do not examine why they want to reduce the awesome variety of human moral concerns into neat, impersonal, categories, or want to construct universal principles, or why they value objectivity and duty, and denigrate attachment and emotion. Gouldner writes of this kind of reductionism as stultifying and 'life-wasting'. He prefers a reflexive and radical approach. People

'surmount tragedy when they use themselves up fully, when they use what they have and what they are, [] even if this requires them to ignore cultural prescription or to behave in innovative ways undefined by their roles.' (1977:505)

Williams (1972:9) criticises the futility of contemporary moral philosophy which gives an impression that 'all the important

issues are off the page somewhere'. Its abstracted purity creates unreal dichotomies:

'Almost all worthwhile human life lies between the extremes that morality puts before us. It starkly emphasises a series of contrasts: [] between force and reason, persuasion and rational conviction. Morality [] makes people think that [] without its ultimately pure justice, there is no justice. It's philosophical errors are only the most abstract expression of a deeply rooted and still powerful misconception of life.' (Williams 1985:195-6)

It is difficult to assess medical ethics other than in its own complicated language and theory. We need to find ways of channelling the concepts elucidated by moralists into new understandings of the problems experienced by patients and those caring for them, rather than covering up the problems with neat rules and divisions. We need to develop theories and a language which many people can use in order to share in making medical decisions that are as rational and compassionate as possible. The experience of children having heart surgery helps to point out the inadequacies of elaborate moral theory and to show the urgent need for new ethical understandings of informed consent which will serve their interests.

Many criticisms of medical ethics also apply to those made of functionalist sociology. The next section considers the contribution of sociological theories to the study of informed consent.

A review of sociological theories and methods
in relation to informed consent

Consent is a complex, individual process. In order to summarise masses of data into forms which can be easily comprehended, research reports about consent tend to simplify and atomise the complex, to study general trends rather than individuals, and to fragment processes into sets of isolated events. There is an unresolvable tension in all research between the infinite variety of raw data and its compression into simplified abstractions. This is a particular problem in studying informed consent which involves subtle nuances, strongly influenced by medical and social contexts. Inevitably coding methods and much analysis crudely obscure nuances and abstract events from their context. In measuring the incidence of characteristics of doctor-patient communication (Byrne & Long 1976, Waitzkin et al 1978), or analysing qualities such as touch and gaze (Frankel 1983), details become clear yet the context and meaning of the whole encounter is lost.

Objectivity and positivism

The aims of objectivity are based on the premise that truth can be discovered by rigorous application of rules of rational, impartial, scientific method. A positivist method of imposing order and avoiding bias is to think in the conceptual dichotomies of the Enlightenment, reason/feeling, fact/value, observable behaviour/invisible identity. Because the latter in each pair cannot be addressed through detached objective research methods, they are therefore excluded from scientific study. Positivists attempt to avoid considering intention and feeling, their own and their research subjects'. They also attempt to separate observer from observed and to ignore their interactions. Cases are discussed not for their particularity but for their abstracted common features. As a result, subtle and complex variations are forced into crude categories. This can lead to misleading conclusions based on selected material from which relevant data are excluded.

It is not possible to base comprehensive research about informed consent on positivist assumptions. Informed consent is

about human responses to a medical condition which is perceived and discussed in numerous ways and degrees of certainty and optimism, depending on who is speaking and listening. The knowledge is not a static packet of facts, but is partly formed by whoever is giving and receiving it, by growing awareness and changing circumstances. Consent is charged with uncertainty, hope and anxiety. A researcher who attempted to examine only rational, certain and objective factors would screen out integral elements in the consent process.

Since the 1950s the extensive critique of positivism has led to the conclusion that neither natural nor social science can collect objective facts in a purely logical and detached way. Depending on the subject and method, the sciences vary in how accurately they can control, predict and generalise from their findings. (Bleier 1982) Besides the acknowledged importance of its aim to be as rational, logical and general as possible, science is now also acknowledged to be partly emotional, intuitive and interpretive. Science is a social activity, set in its political and economic context.

Even in a pure science such as physics, the exact nature of physical objects and their relation to the observer is problematic. (Keller 1985) Scientific claims to objective proof have been challenged. (Popper 1959) Scientific training involves acquiring specialised values and perceptions as well as skills. (Freidson 1970; Faulkner & Arnold 1985) Feminists have criticised the claims of medicine and social science to objective truth by revealing their masculine bias. (Ehrenrich & English 1979; Brighton Women & Science Group 1980) Modern science has been shown to be not neutral and value-free but developed to serve powerful and destructive economic interests. (Easlea 1980; Merchant 1982) Phenomenology and feminist sociology also challenge the premises of objectivity by showing that we cannot see without ideas, or theories, of what we expect to see. (Abrams et al 1981) The language with which we understand and report what we see is inevitably laden with values. (Spender 1980) Berlin considers that emotive terms can be more correct than attempts at objectivity. He cites the example of Jews being 'massacred' by the Nazis, they did not just 'die'. (in Bhaskar

1986:75) Positivist attempts to exclude subjectivity by rigorous methods fail to recognise that subjectivity cannot be entirely controlled and therefore needs to be explored and acknowledged rather than denied. (Ramazanoglu 1987)

In order to summarise a very broad literature, I have drawn on Gouldner's work which criticises attempts to preserve a neutral, antiseptic distance between observer and observed. Gouldner identified the cult of objectivity as

'not neutrality, but as alienation from self and society. [It] transforms the weakness of the internal "refuge" into the superiority of principled aloofness.' (1977:103)

Keller, a physicist, drew attention to the ideology of science as

'the projection of disinterest, of autonomy and alienation. [] The dream of a completely objective science is in principle unrealisable [and] it contains [], an image of self as autonomous and objectified: an image of individuals as unto themselves, severed from the outside world of other objects (animate as well as inanimate) and simultaneously from their own subjectivity. It is the investment in impersonality, the claim to have escaped the influence of desires, wishes and beliefs.' (1985:70)

Gouldner considers that when researchers assume their own neutrality, they remain unaware of their own 'domain assumptions' (1977:484) such as their unconscious need for precision, order and control over a reality which is partly chaotic and unmanageable. As a result, 'myths are woven deeply and invisibly' into their work, such as by its 'cool, mechanical language and structure' which obscures human experiences of struggle and uncertainty (p49). People are treated as numbers and as things, instead of as free agents (p50). Rules, masks, roles and social structures are observed instead of individuals (p505).

Gouldner believes that our deepest domain assumptions, hidden inside positivist research, are the need to believe that what is powerful in society is good, and that we hold unanimous definitions of 'good'. Yet these assumptions are challenged when patients talk about hospital routines which they find distressing. Gouldner identifies two main responses to potential tension between domain assumptions and evidence. Functionalists reduce tensions by tacitly assigning 'goodness' to the powerful

and believing that critics belong to a deviant minority. Relativists assert a value-free neutrality which forbids 'the making of any judgements in the goodness dimension, while accentuating the importance of making judgements in terms of potency.' (1977:486-7) Routines are assessed for their efficiency but not for their efficacy because efficacy overtly involves subjective value judgements. There is thus a tendency to assume that medicine is benignly omniscient and to see medical problems as originating in patients' misperceptions or incompetence. These assumptions tend to obscure conflict of interests, to support the *status quo*, and to imply that informed consent is an irrelevant or impractical concept.

Consent can involve conflicting views of what is good. It needs to be seen within the context of research which reveals domain assumptions and acknowledges that research itself is unavoidably set in a political context, which is engaged with its subject, and which takes account of context and contradiction. The argument throughout the thesis is that informed consent is only partly observable and it combines identity and activity, reason and feeling. It therefore needs forms of research which overcome the dualism of positivism, which see the relation between supposed dichotomies and make connections between reason and emotion, researcher and researched and between theory and method.

Overt and covert functionalism in medical sociology

Medical sociology began with positivist and epidemiological studies which took for granted medical theories and values. When Parsons (1951) introduced a coherent theoretical framework which gave medical sociology some independence from medical theories, this was still based on many functionalist assumptions about benign and impartial medicine. Parsons for instance separated reason from emotion and so regarded patients' and relatives' distress as an impediment to reasoned understanding instead of as a potential source of knowledge. Parsons' theories influenced decades of research, to the extent that even his critics shared many of his assumptions. Although Freidson (1970) challenged Parsons' five characteristics of the medical role on the grounds

that doctors were not, say, neutrally affective, he did not question Parsons' assumption that they should be so.

Gouldner shows how Parsons' influence on the Chicago school, on Goffman and on ethnomethodology, (and Mishler (1984) adds on conversation analysis), has led many sociologists to base their work on unquestioned functionalist assumptions about normality, and patient compliance and deviance. Stimson (1974) also points out that patients have been labelled as deviant (e.g. by Korsch 1968) because sociologists have not considered the logic of non-compliance through the patients' experience of harmful, useless or unnecessary treatment. Deviance and noncompliance has only been considered through the medical view of patients, not through the patients' view of doctors. Medical sociologists tend to analyse interaction solely through the medical perspective as in Labov & Fanshel (1977), or only through doctors' initiating and 'causal' statements in Byrne & Long (1976) and Waitzkin et al (1976). Patients' satisfaction with medical information has been confused with their compliance with treatment, as in the study which measured satisfaction by the number of pills consumed. (Stewart 1984)

The concept of informed consent assumes that the views and interests of doctors and of patients can differ and may conflict. These differences can be recognised only through sociological theories which acknowledge contradiction instead of assuming functionalist unanimity of interests. So Sudnow (1967) and Davis (1963) reported hospital practices which must have caused intense distress to patients, but they adopted the 'neutral' viewpoint of hospital staff, who disconnected practices from recognition of their harmful effects. Roth (1963) shared TB patients' anger but did not have a theory to show that it was as valid as doctors' irritation with angry patients. Only when dominant and subordinate behaviour is seen within a critical theory of power, can issues central to consent such as coercion and respect be considered.

In the 1960s, consent was not recognised in medical practice which, at least in American accounts, appeared to function through the coercion of ignorant patients. (Roth 1963; Davis 1963; Sudnow 1967) Sociological theories of informed consent have to

be reviewed within their historical context. Also, in the 1960s, sociologists had not developed theories which challenged medical knowledge. Medical treatment of TB and polio was clearly inadequate, but it may have been preferable to no treatment. Roth and Davis describe hopeless and unnecessary medical regimes but they do not make prescriptions for change, they try to remain neutrally descriptive. The concept of informed consent, however, assumes the validity of dissent, the notion that lay people may have sound and informed opinions which differ from medical opinion.

In the last two decades, consumer and feminist movements, as well as publicity about medical mistakes, have encouraged new confidence in patients' ability to make judgements. This confidence may also have been fed indirectly by sociological theories of knowledge. For example, in 1970 Freidson challenged doctors' social (mis)use of their knowledge but not its actual validity as knowledge. However, theories of the social construction of knowledge increasingly asked how valid, supreme and benign is medical knowledge. For instance, the Frankfurt school of critical theory questioned the influence of scientific ideology and practice on social relations (Marcuse 1964). Habermas (1971) considered that scientific technology intensifies medical power and mediates our understanding of ourselves. Dreyfus and Rabinov (1982) feared that this will adversely lead 'to the organisation of everything'. Barnes (1984) developed Kuhn's theory of scientific paradigms into assertions that medical 'reality' is problematic and a symbolic system comparable with any other knowledge system. Foucault (1976) theorised that medical knowledge is a set of social practices and Armstrong (1983) considered the human body and disease, once assumed to be stable realities, as social fabrications, or modes of discourse.

Such theories 'problematise' realities showing how issues, once taken for granted as clearly defined and agreed, can be subjective, diffuse perceptions. (Wright & Treacher 1982, Berger 1983). When medical perceptions are treated as potentially problematic, rather than as simply factual, their dominance may be challenged, and patients' views can correspondingly increase in validity and importance. Accepted knowledge and beliefs are

no longer seen as inevitable; it is possible to work towards a more complex understanding of their meaning. The concept of patients' valid dissent to treatment (not just to research) can then be recognised. (Molière, Shaw, Wilde, and countless others recorded public scepticism about medicine; the academic establishment is taking longer to accept the proposition that patients can make informed critical judgements.)

Problems of relativism and truth

When positivist claims to truth are challenged, everyone, scientists, patients, sociologists, has the same difficulty in justifying the validity of their beliefs. Theories which enable fuller examination of patients' views can at the same time challenge their truth and relevance. Bury (1986) points out the limitations of social construction theories, many of which he considers are overstated and if taken to extremes can lead medical sociology into relativism, even nihilism. Trigg (1985) warns of inconclusive and excessive reflection. If doctors and parents cannot be trusted to say what they see as the truth about the child's treatment and interests, or if there are no such truths, informed consent and statements about it cannot have any reality or validity. Yet neither can the theories which refute reality have any claim to validity, and so on in endless regress. Adverse effects of such relativism can be that no epistemological or moral base is left from which to evaluate harm and benefit. Theories denying the reality of the body and of disease, also deny the reality of painful surgery, death and grief.

Much medical sociology purports to be descriptive and impartial, to describe what is happening without making overt judgements about what is normal or ideal, to be a mirror rather than a lamp. However, the ideal of informed and voluntary consent is partly moral, so research about consent unavoidably has evaluative, prescriptive and partial elements. Being tied to invisible thoughts and feelings, morality is not readily observed or recorded in empirical research. Sociology has tended to concentrate on observable activity even, as in Goffman's work (1961), to the extent of bizarre separation of behaviour from motive, so that, say, mental hospitals appear to function without

a purpose. Goffman believed that individuals are not concerned with

'the moral issue of realising standards, but with the amoral issue of engineering a convincing impression that these standards are being realised. [] We are merchants of morality.' (1956:156)

This leads on to the further problem of undermining acceptance of the meaning and substance of talk. Discussion of children's defects may then be treated as if construction of the account is more significant than its content. (Voysey, 1976, Baruch 1983) An example is the following ethnographic analysis of parents' accounts of their children's heart defects and treatment.

'The framework of the research was sociological. This meant that the analysis of what parents said was not treated as a report upon their feelings or psychological adjustment to the situation. Instead, we preferred to treat parents' accounts as appeals to idealised stereotypes of 'normal' parenthood and 'good' adjustments. Following Voysey (1975), the fact that most parents report that they are adjusting well [] has not been treated as a report on actual family behaviour but as a product of the kind of responses which they assume to be morally legitimate or appropriate.' (Silverman, 1983:318):

This approach creates dichotomies between feelings and statements, actual versus normal or good behaviour, appropriate versus real accounts, social versus psychological responses. Silverman raises important issues about how everyone has a different perception of reality, especially of complex interactions, how people project their inner mental states onto experiences, and how moral self-justification is an element of talk, (although this is not similarly stressed in the talk of authorities such as doctors or sociologists.) Yet, if these assumptions are taken to the extent of discrediting parents' reports, it would not be possible to observe the process of informed consent through parents' accounts because one would not expect to elicit data which tallied with the subjective views of other participants or with observable records. Not only would the sociological study of informed consent through parents' accounts be futile, informed consent itself would be perceived as an empty formality in which doctors and patients produced

responses they assumed to be 'appropriate'.

Research which considers the nature of proxy consent has to look beyond presentation to deeply felt moral obligations. Such research is very difficult to defend against criticisms that it imposes unfounded interpretations, criticisms from those working within traditions which accept work such as Goffman's as a valid account of humanity.

One answer to Goffman is that his assertions about 'merchants of morality' are not, as he describes, amoral but are immoral. Gouldner (1977:384,487) considers that such relativism in ethnography and ethnomethodology loses 'empirical realism and moral sensitivity', as when sincerity or love are reduced to 'maudlin sentimentality'. Proxy consent to a child's heart operation loses its meaning if parental concern is devalued in a behaviourist sociology.

Trigg (1985:36) discusses the problem of believing accounts, and although he is writing about religious faith, his words equally apply to parents and doctors talking about children with heart defects.

'Is Christianity true? Sociologists would immediately say that it was illegitimate for them to deal with such a question. Some would reject the idea of objective truth []. Others would say they wished to 'bracket off' the question of truth, and merely look at the fact of belief []. By trying to ignore questions about the content of a belief, [sociology] fails to take seriously the fact that to the person holding it, the most important aspect is that it is true. [] Any sociological interpretation which undercuts this, falsifies what it is interpreting. The central feature of religious belief, as of theories in science, may well lie in its claim to be an objective reality. [] By side-stepping issues of truth and falsity, sociology has often forgotten the importance of claims to truth. Ignoring that can appear tantamount to assuming their falsity.'

Side-stepping issues of morality and truth, on the grounds of methodological difficulty, evades a central premise concerning informed proxy consent: that doctors and parents sincerely express what they perceive as essentially valid beliefs about the child's interests, although their beliefs about children's individual and collective interests may differ. I have therefore accepted people's accounts as valid at the time of speaking, as based on reasonable knowledge of their experience,

on an ability to retell it and as concerned with important issues besides moral self-justification. Sociologists accord these minimal courtesies to colleagues, and the concept of valid consent founders without them. An account may be only a partial expression of complex issues and may vary with time and place. People believe different contingent truths about a single event. Yet these contradictions differ from the untruth of deliberate misreport. I will assume that truth, like informed consent, is an ideal that we can be aware of even if we cannot completely define or achieve it.

Problems of validation

In all research, questions remain about validation which can only partly be answered. The validity of my research depends on the validity of the theories through which it is understood, on how competently the material is collected, reported and analysed, and how nearly the report accords with the differing experiences of the families and staff in the two units.

After a long discussion of problems of validation, Acker et al (1983:431) offered three criteria of adequacy in their research report about in-depth interviews with women. First, they aimed to give a 'true and valid' reconstruction through an adequate social theory, interpretation and findings so 'that our research results fairly and accurately reflect the aspects of social life that we claim we represent.' Their second aim was that 'the active voice of the research subject is heard in the account' when people express their essential thoughts and feelings and are able to change their accounts as, through a series of interviews, they attain a clearer understanding. Third, they thought that research is valid if it 'reveals underlying social relations'. This partly depends on working with theories which relate the visible to the invisible. I attempt to do this by considering invisible issues such as intentions, emotion, and inequality in relationships in three ways: by described^{ing} observed words, actions, silences, use of furniture, and so on which explicitly or implicitly concern these issues; by discussing these issues in interviews with the people involved; and by interpreting possible relevant meanings in the data.

Acker et al believed that their criteria could be achieved when the researcher does not attempt a vain detachment but acknowledges her subjective involvement and gives some account of the research process, and not just of pristine results. Methods are usually hidden in positivist research which seldom explains how and why initial questions and hypothesis were selected or the nature of the 'raw data' before it was converted into neat tables. Of the countless reports on informed consent, all potentially different yet valid, my account is particularly about the parents' view because of my own experience as a parent in hospital and the way that many people I talked with probably identified me as having more in common with parents than with professionals.

Gilligan (1982) found that men tend to use language to aim towards logic, clarity and general rules as a means of controlling experience. In so doing, unlike women, they tend to move away from emotional and contingent issues, to lose sight of moral problems latent in personal experience, and to avoid using language as a medium for exploring feeling or confusion. This process is exemplified in research which emphasises abstract categories and theories, cutting out variations and details in order to demonstrate clear results. Acker challenges these assumptions by trying to use research interviews to explore change and uncertainty with actively involved subjects, and I have attempted to do this, since the consent process involves so much change and uncertainty. The disadvantages are that research work and findings are relatively inconclusive and lengthy. The intention is to produce fair and accurate reports close to the original experiences and to attempt to increase understanding by showing variations, problems, uncertainties and contradictions.

Context

Schutz's phenomenological theory of finite worlds of meaning defines 'context' very narrowly. It creates sharp divisions between medical and parental understandings and between each step of the family's hospital experience, assuming impassable barriers in communication.

'Man's thought is just spread over subject matter located within different and differently related levels and they are

not aware of modifications they would have to make in passing from one level to another.' (1962:76)

The patient's everyday 'life-world' and the medical world are assumed to be incompatible. Yet in practice the worlds do overlap. Patients and doctors talk together and make sense of their encounters. Informed consent is about the meeting of different worlds and can only be studied by overcoming such phenomenological divisions.

Miszhler (1984:95f) shows how insistence on separating worlds of meaning has supported 'medically dominated', normative and functionalist assumptions. These have obscured the way doctors retain power when patients interrupt the dominant 'medical voice' with the voice of the life world. If patients refer to personal or social matters, 'physicians rapidly repair such disruptions to reassert the voice of medicine', by ignoring all but narrowly clinical issues. Miszhler shows the importance of examining connections between the worlds. He argues that doctors' exclusion of personal, social and affective details prevent them from understanding the nature of patients' problems. He gives examples of coherent and beneficial encounters when doctors talk with patients in the voice of the life world. (p142f)

In order to examine informed consent, sociological theories are needed which see connections between medical and parental understanding of the child; between each step in the process of informed consent; between personal experience and growing understanding; between hospital routines and individual reactions; between identity and activity. 'Context' needs to be broadly defined as the family's whole experience of the child's illness and treatment, or as the NHS organisation of paediatric cardiology.

Human nature

Information and the expression of voluntary consent are both meaningless unless they relate to some form of actual thought and experience and not just to appearances. Yet sociology which confines attention to *activity* (including the structuring of accounts) obscures *identity*, our feelings, thoughts and experiences. It undermines concepts of consent as a precaution

against suffering. To have any meaning, suffering has to be more than appearance or claim; we need to explore how it affects our physical and mental experience.

Seidler notes the tendency in the human sciences to reduce human nature to two extremes: ahistorical, unchanging essence, or else simply a product, a 'social and historical construct existing in different forms in different societies'. Between these extremes

'a whole language of moral and human experience is declared redundant. [] Either human nature exists as a definite set of qualities, or else it is historically determined. We aren't left any room to consider the *nature* of the historical formation of human nature.' (1980:117-8)

My theoretical problem was to find means of exploring the social construction of informed consent in relation to human nature and need. Children's heart surgery concerns the child's actual mutilation and pain, parents' attachment to the child, the reality of morbidity and death, and medical efforts to overcome physical problems. These issues can only be considered through acknowledging both our common human nature and the way our experience is filtered through social and personal perceptions. We are powerfully influenced by society. It

'penetrates every area of our experience, so that our very dreams, passions, anxieties and fears are deeply influenced by the prevailing ideology.' (Seidler 1980:144)

So, for example, a mother asked for heart transplantation for her two small daughters with incurable heart disease partly because of prevailing social mores. She said, 'My sister died of the same cardiomyopathy on the day of the first heart transplant. I feel I owe it to them to ask.' Yet, her response was not wholly constituted through discourse or observance of social norms. Our responses are also grounded in a confusing physical and mental life, in our activities and relationships. We struggle to understand through conflict and change. Parents, doctors and nurses are all striving to find better forms of care. Their ends and means differ, partly depending on their differing concepts of human nature and need. Informed consent can be a meeting point where these differences are negotiated. Narrowly static or

constructionist theories of human nature tend to limit our insight into these differing concepts and into the intense and changing experiences of families and staff in the context of the cardiac units. Exploring these emotive areas raises serious problems of validity yet avoiding them raises greater problems of producing limited and misleading knowledge.

Reason and emotion

Consent involves invisible, rational feelings which have received little attention in sociology. Graham's theory of care suggests means of examining these feelings in empirical research. Graham (1983:14) shows how experiences such as caring, which include both thinking and feeling, activity and identity, our material existence and our consciousness, 'slip between the tight conceptual categories of the social sciences'. We have to face 'the deficiency of a scientific apparatus which is blind to the very phenomena we wish to make visible'. Material and active aspects of caring, the economics, politics and power relations have been studied within social policy; the personal identity, emotional and symbolic significance of caring has been explored by psychologists. In such partial analyses, integral and 'interlocking' features are dismantled and fragmented by social science and reconstructed into the diverse perspectives of caring either as labour or as love. The effect is to lose 'its most distinctive and compelling qualities', the 'everyday experience' of caring as a fusion of labour and love. (p29) Graham believes that we need to consider personal and public/political understandings of care together in order to see tensions between them.

This involves drawing together dichotomies assumed in many schools of sociology mentioned earlier. Hochschild's paper The sociology of feeling and emotion (1976:281-3) develops theories which help to overcome dualism between reason and feeling. Hochschild argues that the common avoidance of feeling and emotion in social science 'seems to be based on two images of the social actor'. The *conscious cognitive* actor rationally calculates means and ends, as shown for example by Goffman's studies of behaviour in which little attention is paid to feeling

as motive or influence. On the other hand the *unconscious emotional* actor is driven by motives and instincts which bypass self-conscious analysis and therefore are assumed to be understood more clearly by the social scientist than the actor, for example in work influenced by Freud such as Balint (1957). Reasons for the avoidance of examining feeling and the lack of theories within which to examine it may derive from the high value our society places on reason and on objective, scientific examination of measurable qualities.

'Through the prism of our technological and rationalistic culture, we are led to perceive and feel emotions as some irrelevancy or impediment to getting things done.' (1976:281)

Hochschild advocates the use of a third image to enable consideration of conscious feeling in sociology, This helps to overcome the 'confusion between rationality and emotionlessness' and the implication that emotions are not integral to rational action. The image is the *sentient* actor who is both conscious and feeling, neither a 'bloodless calculator' nor a 'blind expresser of uncontrolled emotion' but someone responding thoughtfully to feeling.

Feelings are elusive and often mistaken or deceptive in their origin, their interpretation, expression, and in how they are perceived by others. Yet the decision to exclude them as unreliable data reinforces at least three problems which have already been mentioned; inaccurate portrayal of human activity separated from integral emotions which give it significance; reinforcement of the medical denial of feeling instead of exploring this problem which can cause distress; unawareness of distress, anxiety, and the silence of people who are too bewildered or afraid to express their anxiety. Attributing feelings and intentions to people who do not explicitly state them during interviews or observations has been labelled as elitism which should be avoided. Yet this response may be seen as itself elitist since very often silent people are dependent; ignoring their problems does nothing to further their interests and may suggest to those with authority to make changes, that change is unnecessary.

Having pointed out the problems of separating out and denying

feeling, Hochschild then seems to step back into the problem when searching for a solution. She proposes an elaborate analysis of feeling rules, a common method in sociology of attempting to control subjectivity by devising systematic means of understanding rules governing everyday life. I have not used this method of rule analysis, because I find it unconvincing. There is no evidence that our responses are so rule-governed, certainly to the extent assumed in the theories, for instance of Hochschild or Voysey (1975), and as Giddens says (1976) no system is given to explain how or why rules are selected. Rule theories are based on separating our feelings from our reason, assuming that we are governed by social norms and not also by our feelings and needs. Developing Hochschild's concept of the sentient actor, both conscious and feeling, I have attempted to observe, and to listen to people talking about, a thinking, feeling experience. I aim to report their experience as far as possible through their own words, but also with an imaginative awareness, a kind of knowledge which is described more fully in chapter 4. But first, further details will be given about my research method, partly in order to show the need for a theory of knowledge.

CHAPTER THREE

COLLECTING, PRESENTING AND INTERPRETING THE DATA

'It was extremely difficult to analyse process, even though we had at least some relevant data. We still tended to look at our participants at one interview and then at the next, observing the changes but unable adequately to account for the intervening process. Yet, that process may be most important to understand if we are to comprehend the ways the larger structure penetrates the life of individuals, as well as the ways that individuals in their daily lives both reproduce and undermine that structure.'

(Acker et al. 1983:434)

The dual nature of consent, being both informed and voluntary, and its quality as partly an invisible and contradictory process present problems for empirical research. This chapter considers the problems and ways of partly resolving them. It also explains the limitations of certain sociological methods and my reasons for choosing an exploratory approach towards understanding both consent and methods of doing research about consent.

First, methods of observing and interviewing are described. Second, problems of reporting my observations are reviewed, including some related problems of positivism and functionalism. Third, holding and interpreting interviews are discussed with a brief reference to phenomenological theories. The final section describes the theories and methods which I have adopted.

1. Collecting the data

Two paediatric cardiac units were observed for two years from the autumn of 1984. The observations included:

1. 17 outpatient clinics in CH (1) and 57 in HH (1), also 10 joint cardiac clinics in referring hospitals. Clinics were held by 8 consultant cardiologists and 3 registrars.
2. Medical meetings at which doctors review cases and plan treatment: 9 in CH and 18 in HH;
3. 1 bypass* heart operation; 7 cardiac catheterisations* in CH and 3 in HH; also xrays, ECGs and many echoes.*

(1) CH = children's hospital; HH = heart hospital;

* = see appendix.

4. Numerous ward rounds and ward activities, on average 3 days a week for 2 years. My observations ranged from sitting in a corner or joining ward rounds, to talking with staff and families, or helping to lay out a baby after she had died.
5. Staff meetings, including in HH: 16 paediatric unit meetings, 4 psycho-social ward rounds, 3 nurse support meetings run by the social worker and nurse teacher, 5 staff meetings about stress run by a research psychiatrist, 7 lectures to medical or nursing staff and 2 conferences on cardiology.
6. Formal and informal planning meetings in HH about: a new hospital, use of space and facilities in the children's ward, children's outpatient clinics, and support services for parents, for nurses and for bereaved families.
7. Meetings of Heartline, an association for families of children with heart defects. I was asked to chair their discussions on informed consent and on preparing children for surgery.

Semi-structured interviews:

1. Long interviews, taped and transcribed, were made with 5 consultants, 3 senior registrars, 7 nurses, and 1 social worker. I asked them to talk about the purpose and nature of their work, their methods and the problems of informing and involving parents. Also how informed and voluntary consent might be achieved. The staff explained cardiac defects and treatment to me. Four members gave four or more long interviews.
2. Notes were made during or straight after further interviews with doctors and nurses, social workers, play workers, a teacher, chaplain, administrators, secretaries, psychologists, psychiatrists, accommodation officers, dietician and technicians.
3. When distributing questionnaires to 415 parents (see below) I talked for at least 10 minutes with 230 parents and longer interviews grew out of many of these conversations. Interviews with 66 parents and 3 adolescents were taped. Notes were made during or after further interviews with 26 parents. Six of the parents gave three or more interviews; some children were readmitted several times during my study. I asked parents to talk about their experience of their child's illness and

treatment, how informed and involved they thought they had been and could be, which aspects they found particularly satisfactory or stressful. The themes were illustrated by very different topics, depending on the age and experience of the child. Parents of babies, for example, talked much about feeding while those of older children spoke about informing the child.

4. Apart from formal interviews, a main source of information was many brief conversations with staff and families recorded in diary form with the observations.

5. While writing the thesis, I sent parts of it to people mentioned in it, asking permission to quote them. Several of them discussed my work with me and as a result I made changes. I could rewrite with more understanding. People had entrusted me with confidential thoughts and some wanted parts withdrawn or made anonymous (which I did). Although I have used only a small part of the data collected, all the rest has been used indirectly in enabling me to come towards a clearer and deeper understanding of the consent process.

Observer-participation

As I had a (CASS) collaborative award for social science which is intended to be used partly for grant holders to contribute to their place of research, at the request of staff, I carried out the following projects in both hospitals.

1. Survey of 415 families 'What the parents think' using a booklet questionnaire about information and facilities provided for families in the two units. A copy of the report which includes the questions and report of the method is enclosed at the back of the thesis.

2. Talking to groups of nurses about informed consent and parents' experiences.

And for HH:

3. 'Nursing satisfaction study' of all the paediatric nurses. A copy of the report, which includes the questions and report of the method is enclosed.

4. Report of replies to a letter sent to 90 bereaved parents asking them to comment on the hospital care of the dying child and his or her family. A copy of the report is enclosed.

5. Rewriting and redesign of admission leaflet.
6. Design of a diet booklet.
7. Amendments to operation consent form.
8. A storybook with photographs to help to prepare children and parents for cardiac catheterisation.
9. With the social worker, raising funds and trying to negotiate improvements in the children's ward furnishings, a room for families, and play provision.

Many of these activities were a potent means of discovering ways in which changes were negotiated, helped or blocked by various authorities. They also enabled me to know some of the staff well by working with them and so to gain a detailed picture of the unit. Becoming a fairly accepted part of the unit took so much time that it could only be achieved in one hospital. The consent process embodies so many nuances and viewpoints that it is hard to summarise even with detailed knowledge of the unit concerned. I therefore concentrated on observing and writing about HH and used CH partly as a control which, by contrast, enabled me to understand aspects of HH more fully. In both hospitals there were very friendly and helpful individuals. One reason for concentrating on HH was that some doctors, sisters, the nurse teacher and social worker were particularly helpful. Another was that there was space to sit and watch without being in the way. This was difficult in the small CH rooms.

It is possible that routines were affected by my presence but because I was there so often people were unlikely to 'keep up an act'. Also the units were public places, with crowds of observers and visitors, which probably permanently affected hospital practices. These tended to be formal, or of a high standard, or fully explained, because being observed was part of the routine. In one quieter clinic where parents tended to speak about intimate issues, although I was the only observer, they still spoke much more freely there than in other clinics. This clinic's consultant would involve me in holding and playing with restless children. Many other clinics showed how children can severely restrict adult conversation, and in this clinic I found how occupying the children can lengthen and deepen the adult

discussion. As I was not aiming to measure how much parents participate in clinics, but to explore the factors which encouraged or restricted their share in discussions about surgery, my interventions were not a matter of distorting representative data but of increasing the range of observations.

I aimed to obtain the informed consent of the subjects to my research. In HH each family was given a note asking permission for me to observe and record their outpatient session and explaining the research project. No one refused permission in the clinic. In CH I was asked not to give out my note because research was considered to be a normal part of the clinic, not something to ask extra permission for. I was to be counted as just one more researcher and 'part of the team' because 'social research is as important as medical research'. While grateful for this friendly encouragement I did not tape-record clinics where I had not formally asked parents' permission if I could be present. Many of the staff did not wear a uniform or white coat, so in order to avoid seeming part of the hospital establishment, I introduced myself as a student doing research at London University on parents' consent to surgery.

I had expected parents to be reluctant to talk in the units about some aspects of the consent process, and planned to carry out home interviews. However parents spoke freely in the hospitals and the two home interviews did not seem to add information. All other interviews were therefore carried out in the wards, parents' sitting rooms just outside CH wards, or the hospital canteens. I wanted parents to talk while they were going through the experience of their child's admission, and were searching for ways to express it, before they developed a well practised account in retrospect.

Three parents in the wards said they did not want to be interviewed, a few others said they were busy and I did not go back in case this was an excuse. A few others seemed reluctant after we began talking and I thought that they had felt unable to refuse. Although talking with them was difficult, abruptly stopping seemed equally awkward with parents who seemed depressed, so I would leave after a short interview. I avoided talking with parents who looked upset. Several parents asked to

talk with me or asked for the questionnaire.

In the clinics, I took notes of almost every consultation, the timing, order of events and movements, who attended, the child's age and condition, the outline of the discussion and many detailed verbatim notes. A few sessions were tape recorded, but these were difficult to transcribe, people tended to drop their voice at crucial moments. Tapes might seem a more objective record than my notes, but much of the clinic activity is nonverbal so tapes retain only a partial impression, whereas notes gave a clearer picture and often enabled me to recall the actual session and remember further details.

Sometimes, as people being interviewed watched me write, they wanted to change what they had said and search for words which fitted their thoughts more exactly. I wanted them to think this was partly 'their' interview, part of research which they could regard, not as *of* or *about* them but, as partly *by* and *for* them, as advocated by Smith (1979) and Oakley (1986). Some parents said that the interviews helped them to become more consciously aware of their own ideas and questions. The interviews altered the consent process, becoming part of it, for some families. Not, I hope, in planting my ideas, but through questions which prompted parents to examine their experience more closely than they might otherwise have done. The writing of Acker et al (1983) on how women gain deeper understanding through several interviews, and of Sennett and Cobb (1972) and Gilligan (1982), on exploring through loosely structured interviews encouraged me to risk listening to people talking instead of tying them down to set questions. Although very much harder to summarise, loose structures uncovered central concerns to parents and staff about informed consent that I had not anticipated.

Later, talking over thesis chapters with some of the people quoted became an important part of validating the work, especially to check my general summaries and impressions which I did not verify by quantitative analysis, and which families and staff did usually confirm. The response from parents was always to agree with what I had written, to be pleased that it might be used, to hope that it would help to improve care for future patients. Some of the staff said that 'important questions have

been raised', and 'overall it was a fair account'. One said, 'I recognise myself and agree with what you have written but it makes me realise how difficult the work is'. Some found it hard to talk to me about their work. One surgeon asked me to destroy his interview transcript (which I did). Another wrote that he read one chapter 'with some humility' and wanted to keep a copy to help 'repeatedly to review our failings and hopefully to improve our care'. A few said that the overall picture was fairly accurate but too critical in tone.

The most difficult part of the work has been to try to make an honest record of what I perceived, knowing that this would distress some of the people involved. They were striving for perfection in impossibly difficult tasks, and some had helped me most generously. Another problem is that little if any account is taken in sociology of the emotive nature of research about children who are very ill and may die. Many interviews were highly charged. Adults were sad, frightened, angry, and many talked about their sense of responding inadequately to insuperable problems. It was necessary to find a means of including these emotive aspects in the thesis.

2. Problems in reporting observed data

As summarised in chapter 2, by the 1980s positivist, hypothesis-testing research based on natural science models had been largely discredited within sociology. Yet in other disciplines, such as medicine, sociological research is still expected to demonstrate objectivity, facts, typical data and generalisations from samples to populations. Concerned to satisfy the average and the majority, doctors are wary of being misled by 'untypical' observations and by a critical minority. A central problem in writing this thesis is the decision to present qualitative data and conclusions drawn from them in a method considered by some doctors to be invalid, anecdotal, voyeuristic, or subjective. It might seem obviously more practical to use a format generally accepted to be valid, statistical, impersonal and objective. This section is an attempt to explain why I have chosen the former method, and how it can help to illuminate aspects of the consent process which apparently more valid, scientific methods

tend to omit or obscure.

A paper by Silverman et al (1984) helps to illustrate the choice of appropriate method, because it raises problems about selecting and validating research material. The report is not typical of their work, but is used here as an example because it is about the same outpatient clinic which I observed later. The article is an important attempt to report sociological data and conclusions in a format which doctors consider valid and therefore are likely to read and possibly to accept. This approach is important because as communication improves between medicine and sociology, each discipline gains from the insights of the other, and patients are then likely to benefit from care based on a broader understanding of their needs.

Silverman's report used the number of questions asked by parents in the clinic to indicate their level of participation. The report, which is about only one consultant's clinic, found that the mean number of parents' questions ranged from one to five per consultation. Commenting on Silverman's paper, Wilkinson, a cardiologist, (1984:697) wrote, 'there remains a real need for objectivity in assessment of our methods of counselling and supporting parents'. However, 'simplistic, albeit scientifically respectable, means to assess a highly charged and complex interaction between a doctor and a patient's family [give] no real answer'.

In the first clinic I attended after reading the report (held by a different consultant) the parents of the first child asked 25 questions. Parents of the next child asked few questions but dominated the tone and content of the discussion by their strong response to the proposed cardiac treatment; the mother cried, the father shouted at her, 'You can pack that in,' and the consultant spoke at length to calm and reassure them in answer to the central question which was never stated (Will the child survive?) ending, 'If it all works we'll be laughing and wishing we'd done it before. Good luck.' The next mother asked six questions and the fourth mother, who had made the appointment, initiated almost every stage of discussion, asking only three questions, but making over 30 unsolicited assertions about her child's health and character.

My clinic notes suggest the limitations of counting questions instead of examining the *quality* of discussions between doctors and parents, when considering parental participation or informed consent.

Questions are only one of several verbal and nonverbal factors which indicate parents' participation in clinics. Assuming that questions are the major indicator of parental participation also assumes that the parents' role is mainly interrogative; this may not be so.

The amount of questions varies considerably between cardiac clinics and consultants as well as between parents, so that considering only one consultant's practice may miss influences which are revealed by comparing different clinics.

It can be difficult to define a question. For example, I observed a mother's statement, 'She's been bleeding from the wound,' being treated as a question in that it was answered by an explanation about wounds healing. Attempts to select objective indicators in interactions, such as 'questions', are inevitably based on subjective definitions of what is a question and the difficulty of sorting such fluid material as talk into firm categories.

Counting questions conveys nothing of the quality of the participation. For example, questions range from, 'Shall I put him on the couch? Shall I take his vest off? Here?' (3) to 'Can she have her heart operation soon? Because then she can have her ear operation and the longer you leave deafness...' (1) Three questions implies greater participation than one, but the first questions are incidental and seek permission, the second kind suggests that parents want to share a major part in decisions.

An important issue is the different intention and effect of questions. Some questions express trust and respect for medical authority by asking for expert information, say, about the heart defect. Other questions can imply a wish to challenge medical decisions asking, say, about the choice or retiming of treatment, about its risks or adverse effects. The second type of question can be more difficult for parents to ask yet, if consent is to be informed and voluntary, they need to be able to discuss their doubts about medical opinions. Difficult questions may not be

asked explicitly, although they may be inferred and much discussion may be addressed implicitly in response to them. For example the mother who cried and the father who shouted could be interpreted as expressing high anxiety at the risk of treatment and asking for further information and reassurance.

The need to interpret the intentions and effects of questions and their implicit trust or blame moves sociological method into subjective forms of analysis. For example, 'she's bleeding from the wound' is difficult to classify, not only as a question or statement, but also as an expression either of trust in medical competence to manage the problem, or of anxiety about a problem perceived as resulting from medical treatment. Yet these kinds of classifications are integral to a consideration of how much this mother thought that she had given informed and voluntary consent to the operation and all its consequences. They apply in more complicated ways, for instance, if a child is brain-damaged after surgery. When consent is seen as partly a state of mind, the question arises: whose assessment (parents', doctors', observers') is valid? Quantitative analysis not only cannot address the quality of discussion between parents and doctors, it also blots out central issues of complex motive and response.

Silverman's paper concludes from 'objective data' of counted questions, that parents asked more questions when more non-family observers were present. This finding is contrasted with parents' 'subjective accounts' in interviews. The parents said that they asked fewer questions than they would have liked to ask because of 'the crowds' or 'the rush'. (1984:690) The choice of salient measures is an issue here; whether numbers of questions asked (if such a phenomenon could be defined and counted) or parents' impressions of 'rush' or 'crowds' give a clearer measure of parents' participation in clinics.

The report implies that participation is like a game of clearly observable behaviour with agreed rules, and that the sociologist like an impartial umpire is assessing the state of play. Yet human behaviour relates to complex experiences and is open to conflicting interpretations. There can be no single 'objective' view. Silverman's analysis cannot take account of parents' feelings about 'rush and crowds'. This led to the

conclusion that arrangements which served medical work and teaching were also directly beneficial to parents, as they appeared to ask more questions. The paper also concluded that parents blame the clinic for making them feel 'crowded out' in order to 'accommodate their own feelings of inadequacy' and guilt about their child's defect. (p694) The study is quoted by some staff in the cardiac unit to justify the many observers in the clinics as helpful to parents. This illustrates the common observation that research tends to be used for and by powerful groups to reinforce the *status quo*.

In Silverman's paper, the visible and invisible context of the clinic is missing and thus does not show which other factors may have affected parents' participation. During my observations, the doctor in Silverman's paper saw each case for an average of 14 minutes. Three other consultants who did little or no teaching saw patients for an average of 17, 20 and 23 minutes respectively. The first doctor often had the longest list of patients, spent much of each patient's time teaching groups of doctors, and worked an overlapping system of patients in two examination areas, so that almost constantly there were simultaneous activities and an atmosphere of hurrying through a formidable amount of cases and teaching. Parents generally spoke more briefly, infrequently, and impersonally and on a narrower range of subjects in this clinic, than in those of some other consultants, where often I was the only observer. Rather than counting questions to support this point, I will discuss in chapter 5 the methods used by different consultants to encourage or to limit discussion with parents. Clinic time and space are elusive concepts to attempt to measure objectively, yet parents' subjective impressions of rush and crowds connect with observable details in the clinics.

Understanding interviews

Some of the empirical studies reviewed in chapter 2 attempt to assess activities relating to informed consent, such as medical information or manner, by measuring patient satisfaction. The purpose of this section is to show the difficulties of collecting and analysing data to support conclusive results, if the complex nature and context of the data are taken into account. A clear example of satisfaction at HH will be given first.

'It was fantastic, wonderful. In intensive care they told us, "Come as long as you like, stay as long as you like." Everyone, nurses, doctors and anaesthetists would come up and say how well Paul was doing. They'd answer questions about every little bleep. [] We were so lucky because he was very well and strong before his operation. Even so he's done so well. It's a wonderful place here. Everybody is so skilful and so kind.'

I went through transcripts of interviews with parents to group them broadly into 'satisfied' or 'dissatisfied' with the amount of information they were given, with the manner in which it was given, and how much parents felt listened to and involved in decisions. Paul's example stood out as 'very satisfied'. At eight months he had corrective surgery shortly after his defect was diagnosed and he recovered, according to the staff, 'exceptionally quickly'. His parents' opinions were likely to be influenced by their gratitude for his remarkable recovery and by the absence of any problems for which they might have felt they could have been more fully prepared. Successful surgery may lend a rosy glow to parents' memories of how they were prepared, just as postoperative problems cast back shadows which may make parents more critical of preparation before the operation. Paul's case was an example of the kind of success for which the system was designed, and the shared pleasure in his recovery was an incentive for the parents and staff to talk together.

Most interviews were about cases which did not go so smoothly and which could not be grouped into clear levels of satisfaction. Parents were ambivalent, expressing a mixture of satisfaction and dissatisfaction which became more complicated in longer interviews and longer episodes of treatment. In some ways the interviews were like the consent process, the longer they

continued the more clearly defined yet complicated a picture emerged. Parents who said they were almost completely satisfied usually had a child who had rapidly effective treatment. Some seemed to need to state and believe in satisfaction in order to carry themselves through severe difficulties, and to keep up their courage in a crisis, such as the mother who was waiting for her daughter to have a complete atrioventricular septal defect* correction the next day. She spoke of her severe anxiety and depression only in relation to Lisa's shunt* operation two years earlier when she was 'absolutely terrified' and Lisa was very ill for nine weeks after surgery. She spoke with firm cheerfulness and found an optimistic meaning in things which depressed some parents. An army wife, she gave an impression of building up confidence before the battle.

'Now I'm a walking encyclopaedia, so I am very much more relaxed about the whole thing. I mean last time, I was going, "Aah! aah!" [gives loud gasping breaths] but now I'm quite relaxed about it because I understand so much more. I'm very lucky, I've got my child, other people haven't. So I think we're very lucky. [] Obviously with this one which is the total correction there's a far higher risk, - um, 85%. 85% get through it so - um, fine. That's better than 50. So you just - , you know at the moment I'm fine about it. Tomorrow I shall just be -, that's all I shall think about, that my child isn't the 15%.

I don't regret ever giving consent or ever saying that it shouldn't be done because I know it has to be. [] There are far worse children here so it gives you some security, some perspective. There's not so much to worry about your own child. Why am I making -, why am I feeling so sad about my own child, when there's other people with far worse situations? Far worse, um, I'm very lucky so - that's it.'

Objectivity was a problem in these interviews in ways which would not apply in natural science research. Often I felt that I could not ask questions about seeming inconsistencies. Why did Lisa's mother say that she was less anxious about a higher risk operation? She seemed to depend on arranging her knowledge in a certain pattern of emphases which balanced rational awareness with feelings of confidence. She was not avoiding truths, but interpreting them with an optimism which made her feel capable of getting through the next few days and helping her child not to be afraid. Denying her fear was her rational response and I had no right to shake her confidence by asking probing questions in the

interests of objective research. Like the hospital staff I was relating to parents who were struggling to sort out their own level of balancing rational understanding with emotional stability.

In talking with parents, it was difficult not to be drawn into their work of finding a balance between ignorance and too much confusing knowledge, or between anxiety and hope; there was always the risk of harming them by upsetting any fragile equilibrium they had found. Many parents would quickly respond to any hint from me of hope or pessimism, not because they thought I was knowledgeable but, it seemed, with a kind of superstition, grasping at straws to stabilise their volatile feelings, like finding good luck in a four leaf clover. They could be so fraught with hopes and fears that much of my attention in interviews was taken with trying to manage the emotional tone of the discussion, often protecting them by not asking disruptive questions. I shared the feelings admitted by many of the staff of often not knowing how to respond to parents' anxiety, and began to realise their professional responsibility for combining information with care.

These feelings conflicted with positivist recommendations for objective, impersonal interview methods in order to avoid 'distorting' the replies. Passive 'respondents' are supposed to give correct unbiased replies to interviewers' neutral, mechanical questions. Interviewers should 'demand respect', and cultivate 'mastery' and 'a manner advantageous for scientific analysis'. As Oakley (1986:233) points out, such methods do not work. Scientific cool detachment contradicts the warmth of 'rapport' necessary to encourage people to talk about themselves, especially about private hopes and fears integral to patients' consent. Interviewers who use blocking mechanisms, similar to those used by doctors to control discussion with patients, are liable to confirm rather than to question assumptions about the limitations of patients' knowledge. Positivist interviewers are supposed to refuse to answer any questions asked by the interviewee, they should 'parry' them or 'laugh them off'. Oakley shows that this response would be ludicrous during her interviews with pregnant women when, for example, someone

anxiously asked her how a baby is born. Oakley considers that the masculine paradigm of dominating, exploitative, interviews discourages characteristics generally held to be feminine such as being sensitive, intuitive and emotionally involved. (p237) Her criticisms leave open the problems of validating subjective emotional interview material, yet 'real science' which neglects emotion gains only an inadequate understanding of human experience.

It was difficult for parents in the ward to manage the barriers between inner life and outer appearance. They spoke of their shock and anxiety but made great efforts to hide these from adults, their child, even perhaps from themselves. They seemed to be standing on the borders of their private, expressive, family world and of the public instrumental world of the hospital. One mother said,

'Everyone here is trying to keep a stiff upper lip. That father over there is the only one who is behaving normally. He's in tears because the daughter he loves is going to theatre today and she may die.'

The parents had to find ways of managing private turmoil in the public institution and many needed some protective barrier of reserve and dignity. Another researcher in one of the cardiac units, looking at family stress, reported his interview with a very reserved mother to a nurses' meeting.

'At one point in tears she spoke to me about her deep shame at giving birth to an imperfect child. I felt this was her level of truth, where she's at and whatever else she is or does rests on that. I think when people don't say how they feel it's not just for themselves but it's also for you. Whether you can take the pain of knowing about their intense suffering. Tears come to my eyes when these people talk. Luckily they don't roll out. I keep looking at them and they know I can take it.

I get the feeling we're peeling away the layers of an onion on both sides until we get - . Then I know I've gone through some sort of barrier. It's an exquisite moment, but it's a question of whether my truth and their truth does get through. [] I think I'll have to write up the degree of empathy required for this kind of interview. It's as tough as any kind, like being on a roller coaster. Your guts are heaving but you have to go on.'

This account raises questions about whether it is useful or ethical to intrude so deeply. It does not take account of the unequal relationship between the powerful interviewer, who perhaps revealed little of himself, and the distressed mother who may have revealed more than she wanted to. Yet if distress is avoided in interviews, findings are liable to be bland and misleading. They would reinforce the beliefs of some doctors that the expressive component is not integral to consent, that feeling can be separated from reason and is of secondary or no importance. Instead of reflecting parents' views, this would reinforce a cause of their problems, the denigration of feeling. As it was, mothers tended to narrate their child's illness in terms of their feelings. For example:

'I felt terrible when they told me how serious it was. It really set me back on my heels. But in one way it was a relief, because although I had been worried, now I knew how much I ought to worry.'

This quote represents dominant themes through the transcripts. There is the sense of helpless inadequacy, 'set me back on my heels', yet also the connection between knowledge, feeling and morality, 'I ought to worry'. Many parents gave graphic and deeply thoughtful accounts of their experience without, I hope, feeling that too many layers of reserve had been peeled away.

Gouldner (1977:25-6) thinks that much sociology, in describing how things *are or appear to be*, thereby prescriptively suggests that things are as they are '*supposed*' to be, that 'value-free' sociologists 'confuse the moral answer with the empirical, saying that what should be, is.' Being detached and disclosing nothing of oneself while pressing interviewees to reveal personal matters can be a domineering exercise which results in people saying not what they actually feel but what they think you want to know, especially if you insist that they stick to your set of questions. The results are likely to affirm what you expect to find instead of discovering more about their viewpoint. Bias is inescapable in the unique interaction of each interview because we are responsive people not static data, and as discussed in chapter 2, objectivity is a form of bias.

Sociological methods which avoid recognition of an imbalance

of power can obscure how people are being dominated against their will, in the research interview or in the consent process. Once the nurses asked me to talk to a woman who refused to speak to them. After I had made her the illicit cup of tea she wanted and commiserated with her that, at that time, parents were not allowed in the ward kitchen she spoke freely. Her 18 month old son's operation had been cancelled three times.

'I felt so let down. I want it over and done with so we can get back to reality. You're sort of in limbo. It's dragging on and on. He keeps missing meals in case he can go down [to theatre]. They've lost his dummy and he won't sleep without it. He just screams because they leave him alone in here. [The other cots in the room were empty.] His dad and I and the two boys all sleep in one room. He doesn't like being on his own. We want to get back home don't we, Mark?

This is a good hospital but it's disorganised. The nurses are very good and all that to the kids, but I wish I could stay here, but they make you pay if you stay, and they'd only send me away [to parents' flats outside the hospital]. What's the point of that? He needs me with him. I'll have spent £80 this week, - fares and minicabs. I have to pay a neighbour to look after my daughter. We haven't a phone and if I'm late back she gets panicky, she thinks Mark must be very ill. My husband's taken unpaid leave to be here when Mark goes down, then they cancel it. You're geared up all day for it, then you have to get all geared up again. We're waiting now, but I don't suppose they'll do it today. It'll be difficult to get them back into the little routine at home again when they've been upset.'

One perspective is to consider this account from the viewpoint of some hospital staff: the priority is safe, expert surgery, parents cannot judge the quality of medical care, so if they are anxious they transfer anxiety on to matters they can assess, such as whether they can stay at night. This perspective devalues parents' opinions. It assumes that parents cannot discuss anxiety about surgery directly, and that other concerns which parents think are serious (like staying with their child) are unimportant. It also assumes that parents' assessment of even 'minor' matters is not wholly rational but is a transference; that they are not deeply worried about say, whether they can stay at night, but that talking about accommodation is the only way they can voice general worries about complicated surgery. This viewpoint is implicitly adopted in many studies of patients'

information and consent, which leave 'anxiety' as an undefined nebulous emotion without any specific rational basis. Anxiety is then seen not as rational but as an over-reaction to minor matters.

From the parents' view, Mark's mother was worried about a specific and, for her, the most important matter: the welfare of her family. She avoided talking to the nurses because she was angry and she saw them as 'kind' and not responsible for problems caused by the 'disorganised hospital'. If I had remained neutral when she said she needed some tea, thereby implicitly supporting hospital rules which we both thought were unjust, she would not have spoken to me either. Just before this interview, the ward sister had been telling me about her own anger that so many operations were overbooked and then cancelled and her frustration that she felt powerless to prevent or alleviate the distress this caused. Nurses were put in the awkward position either of agreeing with parents' criticisms, or of defending systems which they saw as oppressive but could not control.

Mark's mother was upset about major and minor details in the hospital system. She sat all day in a hot, dry ward, exhausted from worry and from trying to pacify Mark and his baby brother. Mark was upset if she went away to the canteen yet she needed an occasional drink to enable her to cope. All the big and small inconveniences expressed two distressing messages: the large hospital machinery was indifferent to the comfort and convenience of individual patients and their families; parents were treated as children, expected to be seen but not heard. His mother knew the arrangements Mark needed for sleeping and feeding and company to prevent or soothe his distress, but she was prevented from providing them.

Oakley (1986:246) considers 'objective' interview methods to be 'morally indefensible'. It is only when interviews are based on some equality and mutual trust that interviewees can risk talking intimately, and only then can they take initiative and determine how much they want to reveal and what are their main concerns. For example, Lisa's mother in asserting cheerful optimism said little explicitly about her anxiety but did show how she needed to control feelings and balance them within her

logical interpretation. Mark's mother's concern was about how responsibility for his care had been taken from her and had been substituted by care which she considered inadequate. I wanted parents to determine the tone of the interview, not to have to work to some imposed artificial standard. Oakley used to help mothers to wash up while they talked, because she aimed to give 'the subjective situation of women greater visibility' (1986:245), and thought this could only be done on their own terms, in interviews which were interactions with a degree of reciprocal intimacy and some personal satisfaction to the interviewees. (p246)

So one problem in this research was to respect the interests of the parents and staff I interviewed, at the same time as trying to arrive at some answers to my questions about informed consent. Although the two concerns often coincided, always there were questions which seemed unaskable and unanswerable, which limited how much I felt I could discover, and sometimes people wanted to talk about issues which I did not think relevant but which later turned out to be so. When Mark's mother talked about the kitchen she was talking about inequality between professionals and parents, about coercion and respect, which are central issues in informed consent. If there is such inequality in 'trivial' matters, what kind of equality can parents expect in major matters of deciding treatment? And how do the assumptions and practices in ward routines affect the practice of seeking informed consent? Studies of informed consent usually leave out the social context, following Kantian divisions between the felt, sensible world and the abstract, intelligible world. Yet as Seidler shows (1986), this very divide creates problems and ignores the concerns of dependent people such as patients.

When interpreting interviews there was a danger of standing outside the position of the staff and families, and imagining that by some superior logic I could point out their inconsistencies. The main task seemed to be to understand why their responses made sense to them, but this left the problem of obvious conflicts of interests or of some staff justifying repressive practices. When parents' comfort and dignity were neglected, it was harder for them to become involved in

discussions about their child's surgery. Physically, it prevented some parents from actually being present at discussions, or being able to attend fully to them. Socially, it made them look inferior and unable to contribute on equal terms. Treating parents as dependent widened the gaps between staff and parents not of knowledge but of status. This is why it has seemed necessary to look at physical settings and the social context and how they can influence the quality and content of discussions during the consent process. My research tries to move outside narrow concepts of informed consent as intellectual comprehension and of liberal assumptions that power is not an issue in doctor-patient relationships.

Case studies

So far, this chapter has summarised practical and conceptual difficulties of researching informed consent. In conclusion, I will discuss the main method which influenced the way I observed and interviewed, and also selected, reported and interpreted my findings. Instead of taking isolated aspects of consent, I attempted to make a case study of the continuing process of informed consent influenced by many nuances and factors in the whole context.

The case study method was chosen because it can show how the parts take their meaning from the social and medical whole and are influenced by them. It enables the researcher to arrive at a comprehensive understanding of the group and processes under study and also to develop general theoretical statements about the social structure and processes. (Becker 1968:233) A case study is

'a way of organising social data so as to preserve the unitary character of the social object being studied.[] It is an approach which views a social unit as a whole.' and as a development or process. (Goode & Hatt, 1952:331)

'Clearly one good case can illuminate the working of a social system in a way that a series of morphological statements cannot achieve.' (Gluckman 1961:9)

By connecting dichotomies (thought and feeling, trust and anxiety) the case study can allow for the development of new

concepts needed for understanding informed consent. The 'insider's view' can be given, showing the difficulties for both doctors and patients because contradictions between different kinds of knowledge can be seen. In C W Mills' words (1959)

'The sociological imagination is the capacity to shift from one perspective to another and in the process to build up an adequate view of a total society and its components.'

Change and growing awareness can be studied, and the people researched can retain some individuality instead of being reduced to statistics. (Mitchell 1981, Bromley 1986) The person is the unit of analysis whereas surveys measure traits.

'The rich detail which emerges from the intimate knowledge that the analyst must acquire in a case study if it is well conducted provides the optimum conditions for the acquisition of those illuminating insights which make formerly opaque connections suddenly pellucid.' (Mitchell 1981:29)

Van Velsen (1969) argues that due weight can be given to the choice-taking actor in case studies because they require very detailed and intimate familiarity by the observer with the behaviour and thoughts of the actors described.

As the case study method reports only a few examples, it can seem wasteful to use so little of the observed material. However, quantitative research also excludes much detail from final reports and can only present a small part of the group or process studied, and observing many other instances contributed to my understanding of the meaning in the examples given. Yet fair selection and report is a main problem, as it is in all research. This is just less obvious when data is selected/excluded in the early stages, such as in the design of a questionnaire or tight research protocol, or in the choice of a hypothesis. There are also the same gaps in all research between recorded data (however rigorous the collection and analysis), validity or proof, and conclusions which make inferences about cause, effect, and association. Barnes (1958) contrasted formal quantitative analysis with the qualitative 'Russian novel' approach of the case study with its richness of detail which remains open to the reader's assessment unlike more processed data.

Yet a case study is not a narrative. Mitchell (1981:9,19,20)

sees it as 'essentially heuristic', concerned with analytic induction. 'This process of inference is only logical or causal and cannot be statistical.' Cases are chosen for their 'explanatory power', not for their typicality, in order to demonstrate certain principles.(p24). The basis of making inferences from case material is the validity of the analysis rather than the representativeness of the events.(p6) Examples are therefore reported because they connect elements of a theory. An analogy is research which examines the nature and effects of a certain heart defect but not the frequency of its occurrence. Case studies aim, not to establish how general or typical the reported incidents are, but to conceptualise the general process of informed consent so that we can understand what is going on, how and possibly why things happen, and what improvements could be made given the restrictions of the social setting.

Examples are given because they can occur within given settings. Yet concentrating on unusual instances could give a misleading picture of the units. I have therefore usually used examples which represent many other cases. The first stage of selection was to review my notes and interviews and to become aware of dominant themes and of frequently repeated experiences. Later, while writing about these, I would use one example from many, because it was in the first pages of my notes which I turned to, or because it described a common experience unusually clearly. The third stage was to check through the data again, to get a general sense of whether the matter was common or unusual, or whether a common theme had been omitted. I analysed medical meetings and clinics, expecting that only a few of the themes I thought important would be found in a single session, but I found that all the main themes recurred with several patients within each session. Although my examples are not statistically demonstrated to be typical, most of the cases cited illustrate common experiences because they occur within hospital routines which allow or ensure their likely occurrence. If an example is exceptional, this will be stated and the reason for using it explained.

One purpose of this chapter was to illustrate discussion of research methods using examples from the units which indicate

central issues in informed consent. Two key issues are knowledge, (for informed consent) and power, (for voluntary consent and freedom of decision). The next chapter summarises theories of knowledge and power which contribute to understanding of the consent process.

CHAPTER FOUR

TWO KINDS OF INEQUALITY AND TWO KINDS OF KNOWLEDGE

'Seeing the world comprised of relationships rather than of people standing alone, a world that coheres through human connection rather than through a system of rules.'

(Gilligan 1982:29)

Theories of inequality

This chapter considers how mainly invisible, inaudible issues in consent can be seen and heard in empirical research. Lukes (1974) discusses this problem of matters which are not material objects but are part of the fabric of shifting opinions and values. He acknowledges that inferences in sociological research about coercion (a central issue in consent) are open to the criticism that they are unscientific and dangerous (1979) but he considers that there are worse problems in denying unseen dimensions, and that sociologists need to find means of researching them. Lukes describes three forms of coercion. These are, that someone acts to prevail, firstly, over the revealed preferences of others and, secondly, over their concealed or half expressed preferences. The third form, which Lukes considers the most important yet most difficult to perceive, is when people's beliefs and desires are shaped in such a way as to preclude options which they would have chosen if they had been informed otherwise, and when they fail to see that their interests as they had perceived them are not being served.

'Power is unique among social phenomena in its self-concealing tendency; and in many situations, its observability correlates inversely with its effectiveness, which cannot therefore be measured only by techniques of direct observation.' (Lukes 1979)

Lukes' theory has important implications for the interpretation of patients' seeming or expressed satisfaction about experiences which also cause them distress. Among the vital influences on consent which I have not had space in this thesis to consider are class, race and gender. Instead, I have concentrated on another form of inequality which seems to predominate over these more usually examined forms, as shown in the following example. A successful managing director told me about his relationship with

his son's doctors who, he felt, walked 'like bishops in the cathedral atmosphere' of the hospital. He said that he needed to sense and trust in this medical superiority during his son's months of intensive care, but he was also disturbed by some of its effects.

'Privacy is very important to me. It's these sort of very serious discussions about the baby which in my view should never be in a room where someone else, not directly involved, can overhear because - your, if your eyes are on stalks, and you're thinking about who is listening... If we were in the public ward, it clammed me up. It made me absolutely schtum and angry. [] That something so serious - er [that the doctor] had not gone to the trouble of thinking what my feelings would be and that it might therefore be desirable to have the conversation in privacy. Because if he was not prepared to do that, er, what did this imply about the rest of his decision making capability? [] If he was going to treat the parents like this maybe he would treat the baby - a bit... [] The whole thing is so dreadfully stressful.'

This example raises the questions: Why could not the father ask for the privacy he wanted? Why does a health service, designed to serve patients, perpetuate routines which ignore some of the patients' needs and preferences? Why do not parents discuss their problems on equal terms with the staff? Some doctors were women, others were from third world countries, so that differences of race, class and gender do not explain this father's sense of inequality. Families' dependence is partly determined by the child's heart defect which can be alleviated only through medical skill. Yet this does not wholly explain the way in which families are treated as 'lesser' persons through a whole set of social practices surrounding surgery.

The theory of two forms of inequality helps to answer these questions. Patients' consent combines two kinds of relationships. In one, expert doctors advise lay patients on medical issues. At the same time, in many respects adult patients or proxies share equal status with doctors, for example as adults who work, vote, and so on. Concepts of respect for patients' autonomy and legal requirements for a signed consent form assume a certain equality between doctors' and patients' decisions about surgery. Baker Miller (1976:4f) suggests why inequality in the first relationship, (expert doctor to lay

patient) colours the second relationship (adults sharing responsibility for the child). She identifies two forms of inequality. In the first form, the lesser partner is *socially* defined as unequal, in relations such as parent-child, teacher-pupil, doctor-patient. The essential intention of these relations is to render them *temporary*, to end them by achieving equality, to help the child towards adulthood, the patient towards independent health. The relationship may continue but in another form, one of equality. 'These relationships are *based in service* to the lesser party. That is their *raison d'être*.'(p4) Yet we often fail to foster the movement from unequal to equal. 'Parents or professional institutions often tip towards serving the needs of the donor instead of those of the lesser party.' We do not have an adequate theory and practice. 'We have trouble in deciding how many rights "to allow" to the lesser party.'(p4-5)

Baker Miller suggests that this is partly because we confuse the first type of temporary, socially defined relations of inequality with a second type. The second kind of inequality is *permanent* and defines people as unequal by '*ascription* that is your birth defines you,'(p6) such as by race, class, or sex. Examples of groups defined as inferior are women, black people, slaves, and so on. In contrast to temporary relations of inequality here the terms are: to reinforce permanent inequality; to serve the interests of the dominant group; to reserve highly valued activities for them; to ascribe valued qualities to them such as skill and intelligence; and to describe subordinate groups as innately inadequate so that development towards equality is not possible for them.

'It follows that subordinates are described in terms of, and encouraged to develop, personal psychological characteristics that are pleasing to the dominant group, [] a familiar cluster: submissiveness, passivity, docility, dependency, lack of initiative, inability to act, to decide, to think, and the like, [] qualities more characteristic of children than adults.[] They are then considered well adjusted.'(p7)

The governing tendencies of the second form of permanent inequality affect us so powerfully that they influence our responses within the first, supposedly temporary, relations of

inequality. This partly accounts for the frequently limited success of efforts towards equality in the helping relations of parents, teachers, doctors and nurses. By a kind of halo effect, patients who are medically less competent are perceived as socially less competent, by professionals and by themselves. Often they are disorientated by the strange hospital setting, by illness and fear. However in the cardiac units, the parents' view that they ought to be submissive and the powerful conflicting pressures which parents appeared to be under, both to speak up for themselves or for their child, yet also to be silent, seemed to go beyond these constraints.

Baker Miller's theory of strong psychological pressures which go beyond reason and complicate unequal relationships, helps to explain the parents' conflicts. Informed consent may be seen as a formal recognition of the potential dangers of these governing tendencies and as a precaution against them. Yet it can be understood and practised only when inequality is acknowledged within the contradictions of the hospital organisation. In practice, patients, like submissive children are expected to submit to routines. Hospitals would rapidly grind to a halt if all patients behaved like assertive adults. Yet the theory of informed consent expects independent thought and decision. A further paradox is that parents are expected to be submissive in matters they understand (such as the child's meal times, dress, access to the child) and are supposed to be offered freedom of choice in matters they least understand (proposed surgery).

Baker Miller identifies other characteristics of unequal relations which help to explain psychological pressures informing hospital practices and parents' responses within the informed consent process. The superior group is assumed to have the maturity, skill, experience and knowledge which inferiors lack but need the benefit of; knowledge held by subordinate groups is held to be inadequate or irrelevant. So in unequal relations, not only is, say, medical knowledge highly valued, but as a corollary of this, family knowledge of the child's needs is set aside as unimportant. As a consequence of this process we question,

'how much can the lesser person express or act on her or his perceptions when these definitely differ from those of the

superior? Above all there is great difficulty in maintaining the conception of the lesser person as a person of as much intrinsic worth as the superior.' (1976:5)

Two beliefs are reinforcing one another here. If hospital staff assert, for example, that it is not necessary for a parent to stay with the child during the medical round or at night, dependent people who question this cannot do so on equal terms. Their question is inevitably seen partly as an insubordinate challenge to a superior judgement and therefore as invalid. The undermining of parents' and children's preferences can result from and reinforce the difficulty of remaining aware of 'the intrinsic worth' of the lesser person. Children's fears about being left in the ward at night then appear to matter less, in comparison with professional values of medical, economic and administrative efficiency. Hospital practices can reinforce these values. The staff can cite customs as reasons, 'we always do it this way and have not found any problems,' or 'we do not have the space or the funds'. In this cycle, use of resources is determined by the staff priorities, so leading onto the next characteristic of unequal relations. The caring profession or institution can tend towards serving its own interests instead of those of the lesser party. (p4) So resources are diverted away from psycho-social care.

Consequences of inequality are also 'kept amazingly obscure - in fact they are usually denied.' (p5) Inequality itself is denied, as in the response, 'If they have any problems they can just come and talk to us.' The silence of dependence is interpreted as the silence of satisfaction. 'We never have any complaints,' or 'Hardly anyone wants to stay.' So non-medical problems of families in the cardiac units tend to be set aside, as if medical work does not connect with families' social experience, or only in ways for which the staff are not responsible. Another response is to acknowledge problems but to add, as some of the staff have said to me, 'But they are only here for such a short time,' or 'Some inconvenience is a small price to pay for the treatment,' or, 'They can sort out their worries when they get home/ see the social worker/ talk with their local doctor.' In the hierarchy of the hospital, junior staff who were

in closest contact with families were aware of, and distressed about, their difficulties, but they partly shared the subordinate position and their reports tended to be ignored. Dominants 'do not like to be reminded of the existence of inequality' and its consequences. (p9)

In response to persistent complaints, hospital authorities might set up an enquiry (twice, for example, into HH outpatient clinics), and form a committee to act on the report. However, the committee would be of senior staff who seldom had the time or desire to make changes. In order to preserve stability, Baker Miller says, 'dominant groups usually impede the development of subordinates [] and militate against stirrings of greater rationality or greater humanity in their own members.' (p8) When a new sister made life much easier for families by making sure that they could use the kitchen, that new patients need not arrive before midday and some parents could go with their child to the anaesthetic room, she was criticised by senior staff for 'doing too much too soon.'

Another characteristic is that the dominant group

'has the greatest influence in determining a culture's outlook - its philosophy, morality, social theory, even its science.' (p8)

Theories of inequality illuminate patients' submission within the context of consent which can restrict their freedom to question and disagree with medical advice. and to routines surrounding surgery. The influence of dominant groups,

'thus legitimizes the unequal relationship and incorporates it into society's guiding concepts, [obscuring] the true nature of this relationship - that is, the very existence of inequality. The culture explains the events that take place in terms of other premises.' (p8)

So it is argued: that the whole matter of surgery is covered by medical and administrative complexities which lay people cannot, or are too upset, to understand; or that investing most resources into medical technology and research, without an accompanying increase in social amenities, is in the patients' best interests; or that parents cannot be allowed freely into intensive care areas in case they see or hear things which would

upset them. It is seldom mentioned that these practices serve the interests of the staff, and that some clients disagree with and are distressed by them.

Baker Miller continues:

'Dominants are usually convinced that the way things are is right and good, not only for them, but especially for subordinates. All morality confirms this view and all social structure sustains it.' (p8)

The imbalance between staff and patients becomes apparent if, in imagination, their roles are reversed and patients keep the staff waiting, ignore questions, and so on. It is difficult to imagine the possibility of running hospitals in a more equal way but this is partly because we are so powerfully influenced by the beliefs of dominant groups.

So far, the behaviour of dominant groups has been seen as working against the achievement of informed consent. However, the position is complicated. Families and staff are often distressed by social structures rather than by dominant individuals, by default and unintended effects rather than by deliberate action. Hospital staff endure much personal inconvenience in caring for patients and also benefit patients greatly. They are engaged in saving lives. Patients' dependence is partly rooted in literal dependence on life-saving care as well as in gratitude. Baker Miller acknowledges that superior and lesser partners are often linked in complicated patterns of mutual benefit, and that groups such as patients are not simply forced to be submissive, to some extent they take on this role. It is strange to watch a series of families in clinics and wards submit quietly to routines which they later protest among themselves were inconvenient, even distressing.

Baker Miller's theory helps to explain the paradox of seemingly willing submission. She suggests that history has shown how dominant groups are surprised, upset and angry at initial signs of discontent by subordinates, and usually reject them as atypical. Subordinate groups avoid 'direct, honest reaction' (p10) because this can result in 'hardship, social ostracism, and psychological isolation'. The very conditions which cause problems for people tend to undermine their strength,

and their confidence that they can challenge them and 'risk being trouble-makers' a role which 'flies in the face of social conditioning.' (p12)

'It is not surprising then that a subordinate group resorts to disguised and indirect ways of acting and reacting [through] actions designed to accommodate and please the dominant group [but which often] contain hidden defiance. Put simply, subordinates won't tell,' (p10-11)

except to people they regard as also in subordinate positions such as junior nurses or other families. Baker Miller considers that we all have qualities and potential which are lost because inequality prevents open exchange of knowledge. Dominant people are unaware of their effect on others, subordinates (such as women or patients) believe prevalent theories that they are inferior. (p11) 'Mutually enhancing interaction is not possible between unequals' (p12) and neither is voluntary consent. Knowledge is gained through raising awareness of injustice, and through the difficult work of conflict that is creative and not destructive. This needs to be a central task of medical ethics, to draw attention to inequalities and to their possible resolution.

To summarise: there is a tension within the relations between professional and client and between that of equal adults. Our relations of permanent, ascribed inequality so deeply mould our beliefs that they tend to overwhelm our responses within potentially equal relations, and to predominate within relations which have threads both of equality and inequality. This is why liberal assumptions about the autonomous, competent patient or proxy patient do not adequately address the complications of inequality within the current practice of informed consent.

Two kinds of knowledge

The previous section aimed to clarify contradictions in the consent process by differentiating between two kinds of inequality. This section considers contradictions which can partly be explained by showing that consent also involves two kinds of knowledge: knowledge as information and knowledge as awareness. Intellectual scientific information, necessary for repairing defective hearts, tends to predominate in medical thinking. Changing awareness of the personal implications and of the meaning for the child of harm and benefit preoccupies the parents. In order to see how parents come to understand and accept risk, it is helpful to see how the two kinds of knowledge can complement, yet also conflict with one another. After summarising contrasting approaches to informed consent by parents and by doctors, I will consider the nature of each kind of knowledge, using the example of how each perceives pain.

Gouldner describes:

'"information", as empirically confirmed assertions about "reality", whose scientific value derived from their implications for rational theory and whose larger social value derived from technologies based upon them. [Such knowledge is used] to know in order to control' (1977:491-2)

The studies of informed consent reviewed in chapter 2 tend to assume a version of knowledge as information. For example, there is a positivist approach to anxiety, percentage risk, and so on, which assumes that these can be objectively recorded as scientific data. Medical information is presented as a kind of static package of facts handed to patients, impersonal and neutral, encapsulating a consistent reality regardless of who reports or hears it. The results of such studies can provide techniques to help doctors to inform patients more efficiently or to know more about patients' preferences or likely responses. Such knowledge can be of practical benefit yet it may be used to increase medical efficiency and control rather than to increase the efficacy of medical care based on new awareness shared by doctors and patients.

The second form of knowledge as awareness is about 'inward communion' with the object studied rather than 'external

manipulation' of it.(Gouldner:492) Awareness transforms and enriches our understanding, even our whole lives. It is concerned with our changing 'hopes, interests and values', our place in the world and in relation to others rather than our control over them. Social objects are not seen as eternally fixed and apart from us, but we bestow shared meanings on them. Our awareness of the world is through our own experience with it, our relationship to it and our efforts to order our experience. Our knowledge depends partly on our own self awareness.(p493) Information can be stored anywhere, but awareness is part of the person. It is an attitude towards the personal implications of information which can almost always be interpreted as good or bad news, hostile or friendly to our purposes. This thesis will probably be read as strongly hostile or friendly depending on the viewpoint of the reader. Such a relationship is the antithesis of the positivist objectivity which mistrusts the 'treacherous' self and tries to exclude it from the process of information, assuming that 'a bloodless and disembodied mind' works best.(p496) Awareness knows that the self can be a source of valid insights and tries to deepen our capacity to relate to knowledge and to become aware of when and why we are ignorant or resist knowledge.

Knowledge as awareness introduces a different understanding of the informed consent process and the means of researching it. For example, awareness shows that concepts of anxiety are often too complicated, subjective and frequently changing to enable us to base firm, static conclusions on them. We may learn more from trying to become aware of how and why people are anxious instead of trying to measure the incidence or intensity of anxiety. Wishing to understand anxiety is related to respecting it as a rational response, making a connection between reason and feeling which knowledge as information denies. This connection relates to the next two points. Awareness involves seeing contingent influences on the consent process. Each example is individual, affected by the hospital design and routine, the relation between patient and doctor, their language and subjective responses which, in research, are also filtered through the perceptions of the researcher. The consent process is not just a question of

patients receiving medical facts, but of growing awareness, potentially in patients and doctors as they exchange medical and family knowledge of the child and fit good and bad news into new frameworks of knowledge, gradually coming to terms with it. Secondly, the results of this research will not be sets of facts which enable people to predict and manage the consent process more efficiently. The results will aim to raise awareness of complexities and problems, of possibilities rather than of techniques and rules, to encourage questioning of present purposes and methods.

The following example of medical information-giving was described to me by a mother in an interview some months after the event. It suggests that the staff saw knowledge as packets of information and the mother experienced knowledge as growing awareness. When he was a day old, her son was taken into special care.

Mother: Somebody whisked him off and they said they thought there was a heart murmur. After about half an hour somebody appeared and said they thought there was something else more serious wrong with him. They were taking xrays, and he would be put in one of those things - an oxygen box. Then a doctor came and said there was something wrong with his heart and they would be sending him to this hospital. Then a nurse came and said she wanted to check the religion.

PA: Did she say why?

Mother: No.

PA: What did you think?

Mother: I thought he was going to die. I was on a drip and they wheeled me along to special care and the priest came and baptised him and um, then an ambulance came and took him away. A paediatrician came and tried to explain what they thought was wrong but I just didn't absorb it at that stage. It was all too much. I was shattered.

In being 'shattered' and so strongly aware of her own pessimistic interpretation, at the time this mother can make little sense of the medical details, except in their significance as good or bad news, reinforcing her awareness rather than her information.

In order to examine the two forms of knowledge in detail, examples will be given of their separate understanding of pain.

Scientific information as knowledge

The Lancet (31.1.87) reported an experiment in an Oxford hospital on pain relief during surgery on premature babies to close the ductus arteriosus, a blood vessel near the heart which normally closes soon after birth. (Anand et al 1987a) The researchers had been 'surprised to find that major [surgical] procedures were performed commonly with minimal or even no anaesthesia' on premature infants. (Anand et al 1987b) In their study, 16 babies were given conventional drugs: curare a paralyzing agent, and nitrous oxide which induces unconsciousness and some degree of anaesthesia - loss of sensation. Eight babies were also given extra pain relief, fentanyl, and eight were not.

The study found considerable differences between the two groups in the babies' hormonal and metabolic changes. 'The findings indicate that preterm babies mount a substantial stress response to surgery under anaesthesia' but this 'massive stress response' may be 'abolished' by fentanyl anaesthesia which also 'may be associated with an improved postoperative outcome.' Complications and a 'clinically unstable course' were observed after surgery in the babies who did not have fentanyl. (Anand et al 1987a:243-4) The authors commented:

'It is widely believed that [] newborn babies are not capable of perceiving or localising pain and that they may not be capable of interpreting pain since they do not have a memory of previous painful experiences. [Examples are given of apparent responses to pain in premature infants.] Clearly, the perception, measurement, and management of painful experiences in the premature infant are very important topics for further exploration. We would suggest that the degree of analgesia, particularly in paralysed and ventilated infants, can be assessed reliably only by measurement of the biochemical and endocrine markers of stress.' (Anand et al 1987a:247)

One published response to the report, questioned the nature of parents' informed consent for surgery when 'analgesia is withheld', and asked how an ethics committee could permit such a study into

'the wholly unacceptable tenet... that preterm babies are not able to perceive pain. [] I believe this [knowing that babies feel pain] to be only common sense and do not believe it is ethical to do this type of study to try to prove it.' (Wilkinson 1987)

Another reply stated:

'Doctors caring for children are often unaware of the fact [of sensitivity and reactions to pain] in newborn and premature babies. These are easily recognised, even without complex laboratory methods, and they are difficult to interpret in terms other than distress, anger, unease, or, simply, pain. Any experienced nurse or competent mother would have been able to describe reliably how babies react to a heel stab or a venepuncture - not to mention a thoracotomy [opening up the chest for surgery] - when not paralysed. [] Surgeons, who declare infants insensitive to pain [] do so contrary to everyday experience and scientific knowledge.' (Lenard 1987)

The Lancet report and letters suggest that in this context there are two kinds of knowledge. There is 'scientific knowledge', 'proof', 'complex laboratory methods', and 'the measurement of biochemical and endocrine markers'. This knowledge is theoretical, abstract and objective in that the scientist aims to stand outside the patient's experience and to assess it by impersonal mathematical and technical criteria. Pain is defined as physiological (metabolic stress reactions) or cerebral ('perceiving, interpreting and localising pain').

The second knowledge is about 'commonsense', 'everyday experience' and the competence of nurses and mothers to 'recognise' distress. It is based on direct perception, experience and empathy with the patient. The mother and nurse 'know' about pain in the sense of connecting the child's response with their own experience of pain and by subjectively sharing a common human identity. Pain is understood as distress or unease, a complex mixture of physical and mental hurt, fear and need for relief.

Each kind of knowledge has both advantages and limitations. Doctors are expected to avoid over-involvement with patients' distress, in order to be able to plan the best treatment clearly; too much pain relief can be harmful or even lethal. However, too much detachment can result in indifference to suffering or in inflicting pain unnecessarily, such as by demanding the kind of research just quoted. I asked a junior anaesthetist if she thought the study quoted was ethical and she replied,

'Yes. We know the idea that babies can't feel pain is codswallop. But the only way you'll convince some doctors is by this kind of scientific study.'

So informed consent is set in a spectrum of ethical standards concerning sources of knowledge, with at one extreme some doctors who insist on detachment and the integrity of scientific analysis as the only basis for knowledge. At the other extreme are children experiencing pain and some parents and nurses being intensely aware of what they feel to be the child's pain. In the centre, people are negotiating what they consider to be a responsible compromise between common sense recognition and scientific assessment of pain levels in order to provide adequate yet safe relief.

Medicine is concerned with two ethical dimensions. One is the integrity of scientific detachment, the other is the ethic of the appropriate human response, avoiding the extremes of negligence or cruelty, of under or over-treatment. These two dimensions, of scientific integrity and of care are partly at cross purposes with one another. Science values detachment from patients; care values involvement with them. This tension between science and care was illustrated by Nazi doctors' denial of the human response ethic and total adherence to the ethic of scientific detachment. Their research made discoveries which are now used to benefit many patients. Their denial of the ethic of care was made possible by officially classifying the 'patients' as not properly human, thereby severing the connection of a common human identity. This disconnection abolished the possibility of compassion which depends on believing that others share our own sensitivity to distress.

The example of pain illustrates the dangers of a scientific extreme of rigidly objective detachment. Scientists who refuse to recognise distress other than through elaborate 'laboratory methods' are treating patients as if they are objects. This approach can limit medical efficiency. For example, when babies in the Lancet report are denied pain relief and need longer intensive postoperative care. Nearly half the members of the Association of Paediatric Anaesthetists who replied to a survey do not use pain relieving supplements in anaesthetics on newborn

babies. (Hatch 1987) Scientists' assumption that newborn babies do not feel pain, with the demand for proof that they do, illustrates the bias in supposedly neutral science. There is far more evidence to support a basic assumption that babies do feel pain, than there is to require proof that they do not.

Different opinions about the appropriate compromise between scientific detachment and human involvement were held by various staff in the two units, such as when pain relief was necessary for children. Both doctors and nurses criticised one another at times for giving too little pain relief too late but they were all aware of the risks of giving too much. Scientific measurements, which assess adverse effects of giving analgesia rather than of withholding it, appeared to be reassuringly reliable compared with risky, subjective guesses about how the child felt. Pain was so difficult to assess and to manage. 'A lot of the problem is discomfort,' one anaesthetist told me. 'A ventilator tube is like having two fingers stuck down your throat but no drugs can relieve that sensation.' A senior nurse said of the ventilator,

'It must be awfully painful. It makes you want to cough with that bent tube in. You're held down, so powerless and dependent and defenceless. Suction is awful although there is relief afterwards, but it's a nightmare for the little ones when you can't explain. The gag and cough reflexes are very powerful unless you are very anaesthetised.'

Another anaesthetist said,

'Pain is so uncertain. We can't be sure how much babies are feeling. How much is in the mind. It's difficult here. Some people mainly have the goal in mind.'

Safety and ultimate cure were generally valued more highly than relief of interim pain. When the staff were extremely busy with activities which could be clearly identified and managed, pain relief tended to slip down the list of priorities. When parents said that their child needed analgesia, nurses would sometimes say, 'Oh the [drug] round is in only an hour', or 'In a minute,' and they seemed to forget or be too busy. A senior registrar asked a consultant, 'Can we put this baby onto opiates? He has severe angina and nothing has worked for the last 24 hours.'

Opiates would hasten the baby's expected death so that it was appropriate to allow time for the decision, but 24 hours was a long time without pain relief, especially when a child had only a few more days of life.

Knowledge as awareness and involvement

Parents spoke of the child's pain as an experience which they partly shared. For example, it made them conscious of time seeming to move terribly slowly. They saw that pain was emotional as well as physical in important ways which could not be measured scientifically, such as fear and agitation. One mother said:

'The ventilator didn't look comfortable for him. It pulled his face out of shape. [] He was sleeping on and off all the time, but he got very agitated when the pain killer wore off. He tried to cry with no sound but there were tears. It was obvious he was in pain, he was thrashing about. They put some more omnopon in the drip in his neck. It seemed to work quite fast - in about two minutes, but they seemed long minutes. [] We were told before the operation that they could tell even before he woke up that a child would be in pain, but they waited until a child showed pain. I wasn't happy about that. I often said, "He's in pain", and they did something. It makes you wonder what would have happened if I hadn't been there. He did get very upset every time I was asked to leave, and if it kept your child in a happy frame of mind I would have thought it would be more beneficial to stay in with him.'

As the hospice movement has shown, fear can intensely exacerbate pain. A senior nurse said that she found that gently stroking and talking to babies was an effective part of pain relief, and could reduce the need for drugs. Her description of her work demonstrates the value of subjective, sensitive interaction with patients.

'Sometimes a baby will be going berserk and he will need the tender touch. Sam was going loopy, sending his blood pressure sky high. He was angry with us fiddling and sticking tubes down his throat - acceptably angry. He had so much secretion, he kept needing suction, [being sucked out by a tube]. The more suction he had the more agitated he became and the more he secreted, it was a vicious circle. His nose is sore and everytime he moves the [ventilator] tube goes in and out which makes it worse for him. You have to be able to tell the difference between what he was doing and a child who is thrashing about and irritable because he's had brain damage, to tell whether he's becoming ill or

having temper tantrums.

He seems to be the sort of baby who is quite active and vigorous and won't put up with what he doesn't like. And you can calm him down a lot by talking to him and stroking him. He needed nursing and then you might be able to get away without paralysing him.

If doctors saw an inexperienced nurse, not able to handle the situation, who said, "Help, you've got to sedate him, got to paralyse him, I can't cope," they'd go along with the nurse. But you need to stop and see what is happening and whether you can settle the baby down. Doctors are better if they've had babies themselves.'

This example suggests that nursing care is much concerned with becoming closely involved with patients, feeling with them in order to be able to assess and provide appropriate care, and applying knowledge from experience of human moods and relationships. Teaching intensive nursing is also a matter of working closely with inexperienced nurses so that they learn what to look for, as the senior nurse said, 'not just the technical things' but how to interact with patients and how patients subtly respond.

This kind of experienced human response worked to calm the child and the parents to a level where they could manage pain and anxiety. If this calm response was missing, parents felt extreme anxiety, aware of the child's need but helpless to answer it, as described by this mother at CH, while another mother sat with her agreeing.

Mother We get worried leaving them with students. Some are good, some very poor, unconfident. You're frightened if the nurse isn't confident. You don't want to go to bed. They practically forcibly evicted me - well, not that, but it's, "Oh, are you still here?" I don't want to leave her. It boils down to standards of nursing. If you've got confidence, you can go and have lunch, but not if you're worried. And you're worried all the time.

If scientific detachment is too highly valued over care for the child's feelings, there is a risk that pain and anxiety become abstract concepts, which are then discounted as unimportant, because they cannot be monitored accurately. Attention to the heart defect may become separated from attention to the patient's experience of the treatment. Trust in the overall benefits of painful surgery can also lead doctors into discounting pain, such

as the consultant who said to parents of a baby waiting for surgery, 'You'll suffer more than she will. A lot of care goes into seeing that the children do not suffer.' Yet the Lancet letter mentioned earlier, questioned the validity of parental consent which did not involve the parents in considering their child's probable experience of pain. This suggests that scientific information is not an adequate basis for informed consent; it needs to be complemented by knowledge as awareness and involvement.

Voluntary consent as awareness

The nurses' concern with voluntary consent as awareness is illustrated in the following examples of nurses wanting to give families time to 'catch up' emotionally so that they are ready to accept the next stage without feeling rather coerced or being left in a state of unawareness.

The timing of surgery was often uncertain because each stage of the previous operation might be unexpectedly prolonged. Children might be left waiting for hours and then suddenly be called to theatre. When the porter arrived with the trolley. The rush not to keep theatre staff waiting added to the strain of parents taking leave of a child they felt that they might never see again. Talking of these events, a sister said at a staff meeting:

'Sometimes it all seems to go wrong. The child's crying, the parents are crying and I feel like crying. I wish I could call the theatre and ask them to wait half an hour so that I had time to calm everyone down.'

Another sister and doctor were talking of parents who, they felt, did not seem to realise the potential dangers of their baby's proposed operation. They said that someone would have to talk to the parents again to try to get them to understand. When I asked why, if surgery was the baby's only hope, they did not leave the parents in relatively comfortable unawareness, the sister said:

'Because if the worst comes to the worst and the child dies they'd have had no preparation and the shock would be even greater afterwards. I think they can be informed about the technical side of surgery and still not understand the implications of it.'

The sister drew a distinction between rational technical knowledge and actually grasping the implications personally. She described the emotional states she would expect to see, in order that she could be convinced that parents understood.

'In parents just told, say, that there is a risk of their child dying - I would expect them to be tearful. If parents seemed fairly light and jolly and didn't even register any shock, even that blank shock where tears aren't enough, if there's no reaction, I'd wonder if they'd taken it in.'

The sister sees feeling reactions as central to informed consent. Shock and grief are part of the process of growing awareness, not just a behaviour but physical and mental states which enable parents to 'take in' knowledge.

Learning through feeling

Bion's theory learned through child psychoanalysis helps to explain how we learn through our bodies, feelings and thoughts. From babyhood we tend to 'take in' important news first as a physical reaction. The theory also shows the profound significance of the parents' physical-emotional-mental reaction to harm threatening their child. Bion shows how a baby's physical distress arouses awareness and how adult contact is required in order for the baby to develop sensation into feeling and thought.

'The use of the adult as the container for painful states of being is the prerequisite for development within the self of one's own capacity to bear the pain of thinking. (Bion 1962) The earliest forms of communication take place without any mediation by verbal or nonverbal symbols. In a direct and often raw compelling way the baby conveys its feelings to the mother. If the baby is alarmed or distressed, what he does about this is to arouse alarm or distress in the mother. He causes the mother to experience in her own feelings what he cannot yet bear to keep inside himself.' (Hoxter 1977:214)

Just as the baby first becomes aware through sensation, the mother is also first aware of the baby's state, not through verbal or nonverbal symbol (mental interpretation) but through sensation, a raw, direct shared feeling which could be labelled intuition or empathy except that neither word conveys the pre-

thought 'gut' feeling; perhaps language has no word for the sensation which precedes and gives substance to thought. Bion's theory implies that maternal anxiety is a creative force, a prerequisite for human care and development.

Bion's theory also suggests that human communication at any age is strongly influenced by physical and emotional feelings. When parents are made aware of great risk, how can they and the doctors and nurses who are awakening their awareness 'bear the pain of thinking', a pain which is much more than an intellectual problem. One way is to try to deny this pain. Another way is to try to respond to feelings, as Hoxter (1977:215) describes happening in Bion's theory.

'And the mother has to cope with these feelings of alarm and distress in herself, before she is able to respond appropriately and give relief to the baby. The mother who is not too immersed in her own difficulties replies to the baby's behaviour [of cries, smiles,] as though she believes that such behaviour is a meaningful communication which requires to be understood and responded to. Her response is probably an essential prerequisite enabling the baby gradually to build up some form of realisation of his own that behaviour is meaningful and communicative.'

Because they worked closely with very sick children and their families, sitting one-to-one with them all day in intensive care for example, nurses were vividly aware of feelings and of their own need in Hoxter's terms 'to respond appropriately and give relief'. They were aware of families' feelings 'in a direct and often raw, compelling way'. The sister who 'felt like crying too' was one instance of countless comments by nurses of their feeling reaction to distress. A main theme in our nursing study (attached) was nurses' difficulty in knowing how to cope with their own distress and how to respond professionally to families' distress. This underlies the current slogan in nursing, 'who cares for the carers?' The nurse, like the mother, is expected to give relief. Yet she can only do so when she has adequate support to be able 'to cope with feelings of distress in herself', and can work in hospital systems which help and do not hinder her work of giving relief.

Nurses felt a responsibility to believe in the meaning of family's distressed behaviour, to understand and respond to

nonverbal signs, and thereby to help families 'gradually to build up some form of realisation of' the meaning of their behaviour. When we react to news with shock, rage or tears, it is as if our subconsciousness and our bodies have powerfully grasped the implications of, say, loss or danger, well before our minds are consciously able to think through the meaning.

Nurses wanted to ensure that families understood risk clearly and intensely. They could not offer false comfort by denying danger. Yet they needed to offer some comfort in order to help families to 'bear the pain of thinking', to work through their initial shock and come to terms with the truth as they perceived it. The sister quoted above described how she would respond with a mixture of sympathy, comfort, and information.

Sister: They should be able to be tearful. If necessary, to feel private. I would find a screen or draw the curtain because I feel that is a healthy reaction to anxiety. I hope no one would stop them. I might even take the baby away if it's crying and they're crying. Just a few feet away so that the mother can cry without having to be concerned about the baby.

If they were upset after a doctor had spoken to them, I'd stay with them. I'd find out why they were upset and if I were uncertain what the doctor had said, I'd go and find out. If there was a significant risk, I'd emphasise to them it's a risk they're going to have to take if they want their child treated. I'd say, "as the baby's not thriving and will not do well" (we always use euphemistic terms) "without an operation, and the operation is the only means to give him a normal life, so that is their only option". They always agree. It helps them to have a second person saying it. []

If their child is brain damaged or if he dies in theatre, parents feel guilty afterwards. So it's even more important to emphasise to them that the baby needed the operation. It was their only option. All parents agree that if it's the child's only chance, however small, they'll take it.

PA: I heard a psychiatric nurse say that NHS staff tend to want to comfort and quickly take away mental pain, but people trained in therapy try to acknowledge distress and help people to express it. How do you think you should respond to upset parents?

Sister: To comfort them, definitely. They may need reassurance that their anxiety is well placed, but if they are anxious they need to be reassured that they are in a specialist centre. Hopefully this eases their anxiety on both counts.

The sister worked within the contradiction of trying both to increase awareness yet also to reduce distress resulting from awareness, and she does so partly by validating anxiety and thereby respecting parents' dignity through her sympathy. She resolves the dichotomy, assumed in some arguments about autonomy, between respect for persons and sympathetic care, the assumption that caring for dependent people demeans them.

These arguments are influenced by Kant's principle of respect which is 'in no way based on feelings, impulses and inclinations but only on the relation of rational beings to one another' (Kant 1948:96). Belief in impersonal respect for autonomy prescribes offering objective information and leaving the person to make a decision without attempting persuasion. (In proxy consent, there is the complication that staff may persuade or coerce parents to agree to surgery, because the staff believe this serves the patient's interests.) If adult patients (and, in principle, proxies) are left with just technical information and without supportive discussion they may feel neglected. They may need or want someone to help them. The notion that patients/parents can handle medical information impartially implies that decisions are based on clear objective facts, unequivocal moral choice, and pure reason devoid of feeling. Yet some degree of doubt and guilt about submitting the child to risky surgery is possibly inevitable. Kant's concept of 'the relation of rational beings' which denies feeling is not wholly rational, since feelings are an inescapable part of our thinking and relating.

Kantian denunciation of feeling can be a protection against vulnerability to the distress of oneself and others, a way of dealing with pain. One member of the paediatric team said:

'I don't think you can choose a more devastating line of work than paediatric cardiology, always dealing with loss and death and despair and mutilation of babies. If you don't quite get it right they die. You can't even take a year off. Planning scientific research is a way of avoiding pain and guilt and anger. And your impotence and frustration at not to be able to cure all your patients.'

Behaving as if medical information is wholly scientific, precise and without emotional implications can be partly a refuge for doctors. As Seidler (1986:120f) points out, detachment is based

on assumptions such as 'Kant's conception of the person as fragmented between the sensible world and the intelligible world', of a divided self separating reason and feeling. Only in the intelligible world are 'our freedom and autonomy guaranteed to us' because in the sensible world we are driven and constrained by our needs, desires and human inadequacy. Kantian notions of autonomy and consent are abstractions based on concepts of the self which conflict with real experience. Yet the conflict is complicated because each side of the opposing pairs contains essential qualities: objectivity and involvement, science and sentiment, respect and care, reason and feeling. It is necessary to plan treatment clearly and also to respond compassionately. Perhaps both can be achieved when false dichotomies are questioned and connections made between feeling and reason, information and voluntariness.

Sharing knowledge and decisions

The final part of this chapter illustrates the themes of inequality and knowledge through a study of one patient. The example illustrates problems arising when the staff practise detached medicine, and when medical and nursing routines serving many children restrict professional awareness of each child's particular needs. The staff, working in rotas and caring for many patients, see each child in a set of disconnected stages. The mother, involved in a continuing sequence, connects the stages to earlier events and to their effects on her child.

The need for informed consent, not only for major procedures but also for other interventions, becomes apparent. Consent is a means of achieving a degree of equality between parents and staff in order to plan treatment which avoids suffering as far as possible. Professional expertise and parents' compassion (feeling with) are both important. Withholding consent until they are convinced that it is beneficial is seen by some parents as a final sanction and a means of insisting on adequate discussion. Some parents see consent to 'minor' procedures, which they can see and understand often more clearly than surgery, as extremely important. The following example suggests that informed consent should be sought for a wider range of interventions. At present, consent for most hospital procedures is assumed or ignored, so losing opportunities for the staff to become more aware of the patient's needs.

Postoperative interventions are discussed here, partly because they illustrate the overall complexity of consent to surgery, not to a single event but to a (sometimes long) process of treatment. Discussions after surgery helped my research because they were often more protracted, easily observed, and tied into actual details and effects of treatment. Parents became increasingly experienced and knowledgeable about the disease and treatment, about the hospital context, their relations with the staff and the difficulties of negotiating consent. The hourly interaction between the child, parents and staff offered clear examples of how decisions were shared and made. Parents' interviews then became more informative about the nature of consent.

Jane Williams, then aged four months, had spent her life at

the heart hospital. A brief summary will be made from three interviews and several short conversations with Mrs Williams, in the HH ward and canteen. We talked in the ward and also in the relative freedom of the hospital canteen. Surgery successfully corrected Jane's heart, but damaged her diaphragm which became partly paralysed. Jane had difficulty in breathing and gaining weight and she had a series of infections. Mrs Williams was quiet and gentle and very reluctant to criticise.

MW: I've finally convinced them that she must go home. I did feel I was having a battle with them. I got a bit cross at the weekend actually. She's got pseudomonas again.

Mrs Williams explained that pseudomonas was an infection 'that goes round here quite often'. I asked if it was caught from other patients.

MW: I'm not really sure. When I ask the doctors they all say that all the patients with it have different strains. They have antibiotics which stop it from being - from making them ill. But it lurks around in their body afterwards. What made me really so angry last time was that two babies had it. That's where Jane caught it in the first place. Whatever the hospital says, I know that. So they had them both on the other side of this room and they wanted to put Jane with them. The tests showed her infection had nearly gone. So I refused to let her. It wasn't easy because I feel I've got a fairly good relationship with most of the staff. I felt very awkward. They've got to say it's all different strains to protect themselves. I don't believe it. I discovered that although they left her on this side, they had two nurses working in here and the one looking after the pseudomonas babies looked after Jane. And blow me, she catches it again. It was the weekend when at last she was going to go home and she couldn't.

I was a bit numb. I'd been angry the first time because I really did think it was their fault. Barrier nursing - they don't do it properly here. They just play at it. [] They play with one baby then another. Very often they don't wash in between.

PA: What will you do?

MW: That's why I feel she's got to get out once the antibiotic's finished.

PA: What does your husband think?

MW: David ... he was furious when he found she had it again. He gets a bit depressed - about everything. I got very depressed that we might be here another 3 to 4 weeks.

As she talked, Mrs Williams became more certain about her own ideas (that cross infection was the problem) and about her own

feelings. From saying at first that she was a 'bit cross' later she talks about being 'very, very angry'. She gave a sense of the 'battle' being mainly inside herself, in her conflict between wanting to trust and have friendly relations with the staff and wanting to stop measures which she thought might harm her child.

MW: We've done battle with them on more than one occasion.

PA: Battle? Was it rather muted?

MW: Yes, it was.

PA: What do you do when they come from touching another baby?

MW: Well, I can't say anything. They're being nice. It's like a slap in the face to say anything, like telling them how to do their job. [] I couldn't report the nurses because I get on so well with them. It's a bit like sneaking.

Mrs Williams seems to be caught in an untenable paradox, which has been defined (Waitzlavic et al 1967:195) as having three ingredients: a strong complementary relationship between dominant and subordinate people; an injunction that must be disobeyed to be obeyed; inability of the subordinate person to step *outside* the frame and thus dissolve the paradox by commenting on it because that would be insubordinate. The paradoxical injunction for parents was that in order to be responsible parents by ensuring good relations between their child and the cardiac staff, they should respect and trust the cardiac staff. This meant not questioning situations (such as poor barrier nursing) which they saw as doing harm to their child. Jane's mother said at the end of the interview:

MW: I feel I've really got to push to get her out. I'm going to keep asking and not let up and if she's well enough I might tell them. We definitely lost confidence last weekend. David and I made a conscious decision to hold back a bit, as the way things are going, relations can easily break down completely. Because she's always going to be a patient at this hospital. We felt it was in her interests for us to maintain friendly relationships.

Confidence in the quality of medical care is linked with confidence in doctors' awareness of the child's needs and willingness to listen to parents. Communication about consent to treatment contains covert communication about the relationship between the staff and family and about parents handing over to

the staff part of their authority over their child. Difficulties arise when the staff assume that they have an authority and competence which parents doubt but feel unable to question. 'Every language has a structure concerning which, in the language, nothing can be said,' except in a separate 'metalanguage'. (Waitzlavic et al 1967:83) For example, maths has a language of symbols which can only be discussed in the metalanguage of words. Yet with communication we do not have a metalanguage; we cannot step outside the words, thoughts and feelings we use when communicating. Patients and doctors cannot explicitly talk together about problems of trust without threatening the trusting relations between them. They can only keep their present relationship intact by silence about its nature or by commenting to other people outside it.

Mrs Williams explained why Jane's infection worried her.

MW: When babies get pseudomonas they usually have an intravenous line put in because they have two different antibiotics, three times a day and that's quite painful intramuscularly. Jane had a drip set up in her hand on Friday. It came out accidentally. [] They have to put a new line in about every day. When I came in on Saturday she had bruising about her eyebrows and on her chest where they'd been trying to put more drips up unsuccessfully. [] I don't know whether Dr C is good or bad but he's more adventurous and he tries strange places. On one round the other doctors were horrified. They took it out and put it somewhere else because they thought it shouldn't be there. Dr C wasn't there. They didn't exactly criticise, it was more a bit of muttering.

I asked the nurse if they'd tried to put a drip in Jane's head and she said, 'Oh no, they wouldn't put a drip in there.' But later a doctor told me they had tried. Then they decided to put one into her neck so they took her away into the treatment room. I'd probably have gone if I'd been asked because she calms down much quicker if I pick her up. They got an anaesthetist to come and do it because apparently it's quite difficult to put one in the neck. At last he came in to see Dr A, who was looking at a baby in here. He told Dr A that Jane was too distressed, he couldn't get a line in. We heard that because we were sitting by Jane's cot. Dr A left the room without saying anything to us and stayed at least half an hour in the treatment room with Jane and a nurse. Then they brought her back in here and put her straight into oxygen, a head box. Jane looked ghastly, grey, breathing very fast. I couldn't pick her up for a while. I felt they'd spent half an hour trying to calm her.

David and I were furious. David said to the nurse he wanted to make a formal complaint. Dr A came in and was quite rude I felt, a bit off-hand, and a few words were

exchanged on both sides. I was trying to calm Jane down. I was a bit upset. Anyway David and Dr A ended up amicably, both sides apologising to each other.

PA: Was anything gained by talking?

MW: Yes. We made our point. They knew when Jane has an infection she can't take much stress, she gets upset very quickly. We felt she should have been sedated for something as dramatic as that. It's quite unpleasant. They turn them upside down so blood rushes to the neck. She would find that particularly uncomfortable because of her breathing difficulties.

Although Mrs Williams seems to need to think that Mr Williams' comments were useful, 'we made our point', the point seems not to have been taken.

MW: Late that evening I phoned from home and found they'd tried to put in a line again. So when we came in on Sunday she was really ill. The nurses told me they hadn't sedated her. [] Because she was so upset, they wanted to put her back on the ventilator, and I was very, very angry, because I felt they'd made her like that. She was perfectly happy until they tried to put lines in. So they put her life at risk simply to give her antibiotics, on more than one occasion. She has them by injection now and doesn't even wake up, because they couldn't get a line in. I think the consultant told them to try that.

Gratitude for medical skill and life-saving surgery gradually changes to criticism through a series of seemingly painful, puzzling jolts which awakens distress, a 'battle' of mixed feelings. These can only be resolved if Mrs Williams questions her trust in the staff and begins to believe her own observations and the criticisms the staff make of one another. She said, 'I felt the nurses were on our side, even the sister.' Her anger and anxiety, like pain, warn and draw attention to a problem which needs to be thought through rationally. Emotion starts the train of thought and also helps Mrs Williams to pursue it. Remembering that her anger about earlier infection was justified gives her the confidence or impetus to work through the conflict between medical information and her own judgement. It also helps to strengthen her isolated position set against the professional team.

Jane's mother expresses herself in emotional terms to explain and also justify her conclusion. She links intense feeling with Jane's intense reactions ('looking ghastly') and with the

discrepancy she sees between the ideal and the actual practice of barrier nursing. Through the interviews Jane's mother closely associates her own mental state with Jane's physical state. Although she resolves her inner conflict by coming to believe her own opinions, she has difficulty with resolving her differences with the staff. When the doctors are angry at being criticised, Jane's parents try to repair the present relationship, ('both sides apologising'). They do not attempt to create a new, more equal relationship fearing that 'relations can easily break down completely'.

Mrs Williams described further differences with the doctors.

MW: On the Monday ward round they talked mainly about putting her back on the ventilator because she was breathing so fast and not gaining weight. I'd already told Dr B I didn't agree with that because when she's asleep her resps go right down to 40, so she gets a rest.

PA: What should the respiration rate be?

MW: It should be fortyish. Well, Dr B, er, he was a bit glib. He said, "Okay we'll put her on the ventilator when she's awake then." Which made me very angry because I don't think it's a joking matter. I think the ventilator is the most upsetting, depressing thing. It still upsets me to think about it. When they used to try and take her off the ventilator and they had to put her back on, that would upset me more than anything. They'd ask me to wait outside.

PA: Would you rather go away?

MW: Yes. They have to give them a paralysing drug which stops them breathing, and also I have been present a couple of times when her heart rate has gone down or something, and it quite frightened me. I think it is better if you're not there. Although it is worrying to be outside, it's more frightening to be there watching what's happening.

PA: When you say her heart rate goes down, do you find you're watching the machines?

MW: Yes. Well, I used to talk to her when she was awake, and play with her. But most of the time I used to count the heart beats and how fast she was breathing, and watch the machines. [] I was always on edge, but I was happier sitting there than being away. I worried more and got more upset if I wasn't there. I think I'm just over-anxious. I worry about every little thing, - if Jane vomits, if she goes pale for five seconds. I think the nurses - they've got six babies in here and they're used to it. They're never nasty to me but I think they feel I'm over reacting sometimes. It surprised me how quickly her temperature dropped on the gauge when her cover was taken off. I wouldn't have thought twice about that if I'd taken her straight home.

Mrs Williams anxiety was a reaction to Jane's illness, to the knowledge she had gained through watching and listening, and to the effects of the treatment. She relied on the staff to organise the care and decisions and to teach her. It was therefore very difficult for her to question their professional judgement when her criticism was mainly based on knowledge they had given her. Their extensive knowledge was balanced by her particular knowledge of her child. Yet the aims and values of detached hospital care of many babies contradicted the values of involved maternal care of a particular baby. Parents were anxious not to seem to claim more than their child's 'fair' share by some kind of utilitarian measure of the fair share of resources. Yet this measure had an impersonal basis: the amount of care one nurse could give to six babies. The nurses thought that the nurse:baby ratio was inadequate. It bore no comparison to the almost full-time care a mother gives to one well baby at home. Yet in its light, maternal concern for a sick baby can be classified as 'over anxiety'.

MW: To go back to the ward round. They don't like it at all if you do question a decision or disagree with something they want to do. I felt, if they wanted to put her on the ventilator, as part of a plan to make Jane better, I wouldn't mind so much, but they seem to be grasping at straws. Dr B, if he sees a patient, he has to do something. The consultant took his side. He asked me what I thought about her going on the ventilator and I said I wasn't very happy about it. So he said they wouldn't do that, but he made a point of saying it wasn't because I didn't want it, but because she seemed a little better, I ignored that because I was so furious. I felt like reminding him whose child Jane was and taking her home, quite frankly. The antibiotic has made her much better, but I feel she wouldn't be as ill if they'd approached the problems differently. It made her much worse. I think their judgement is very poor.

PA: It was at the weekend. Do you think it was a case of junior doctors panicking and feeling they ought to do something?

MW: Yes. They haven't got the confidence to look at a baby and say, 'She looks all right we won't do anything,' which senior doctors often do. They feel they are the doctor and they must do something.

There is an impression that doctors have other obligations besides those to the child. Junior doctors need to show their active responsibility, senior doctors are obliged to support

their juniors in front of the parents. There were divisions throughout the hospital, such as constantly changing medical and nursing staff rotas (discussed later) which fragmented the care for patients. Senior doctors usually made decisions and junior doctors carried them out. One cardiologist at CH who took a particular interest in family-centred care also listened to junior doctors. I heard an SHO (1) give him a long account of difficulties setting up a drip. Because the consultant listened sympathetically he became aware of what was happening to patients. When consultants left the means of treatment to SHOs and concentrated on the end results they were less aware of the patients' experience and made decisions based on partial medical information. Close working relations between different grades of doctors enabled closer continuity of patient care. For example, they could make it easier for SHOs to 'admit defeat' and ask a more senior doctor to help. Praising one SHO, a sister said that one of her excellent qualities was that 'she knows when to give up trying to put in a line. She knows when the child has had enough,' in contrast to some other SHOs.

Mrs Williams explained that Jane was using up so many calories with rapid breathing that this prevented her from growing, yet growth would help to improve her breathing. Some of the doctors thought that putting Jane back on the ventilator or putting extra calories in her feeds would help her to grow. Some of the nurses said that other heart units, in which they had worked, did not believe in these policies. From an apparent dearth of information in older studies, (Roth 1963; Davis 1963), parents now seem to be inundated with conflicting information from different staff. Somehow they have to sort out the views they find most convincing.

MW: Now I've sort of thought and calmed down. I think they're being unreasonable. Because although she is underweight, a lot of older heart babies weigh the same or less than Jane. [] But they make me anxious because of the ventilator if she doesn't grow. [] I don't think this hospital listens to parents enough. They ask what I think, because Jane's been here a long time, but I feel they're not interested in hearing the answer. [] I think they ask

(1) SHO - senior house officer, the most junior medical grade in both hospitals

about the ventilator because it's my decision at the end of the day. They can't put her on if I say "no". I know that - unless it's to save her life and she's not that sick. [] If a baby's only in for two weeks, parents don't realise a lot of what is going on. But you get to know why they do certain things when you've been here longer. For example, when Jane was breathing at about 90 they used to sedate her a lot to make her resps come down. When they were trying to put the line in, we asked why she hadn't been sedated. Dr A said she couldn't be sedated because of her breathing problems. You get conflicting advice. That kind of thing happens a lot.

PA: If Jane ever needed another operation, would you want to be more informed?

MW: I'd ask a lot more questions and be a lot more wary. I've found they often only tell you if you ask questions, and you don't know what questions to ask - not being a medical person. I think the senior registrar is very, very good. He actually sits down and draws pictures, and tries to make you understand, And he's very patient and explains things thoroughly, more than once if you want. On the round he asks me rather than the sister how Jane is.

Means and ends

A basic principle in medical ethics is respect for the autonomy of the rational person, a concept founded on Kant's practical imperative:

'Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end.'
(Kant 1948:91)

The imperative is no guarantee of respect or care for patients because it leaves open an enormous loophole. Doctors can argue that whatever they do to patients is intended to benefit them and therefore is treating patients as an end in themselves. The end of procuring health is regarded as a form of respect which can justify any means directed towards it. The dilemma which Kant's imperative leaves open is: what does treating someone as an end mean, and who should define the meaning? Mrs Williams and the doctors want to pursue the same end, Jane's healthy recovery, but Mrs William's tends to see each means as partly an end in itself. Barrier nursing, drips, injections, and so on, all have important effects on Jane. Means partly determine ends and artificially separating them can be detrimental to patients. Intent upon the end, doctors may underestimate the pain of the means, especially

when medical and nursing care is fragmented. They may forget that they are using the body as a means of obtaining certain results, instead of always treating the patient with as much care and respect as possible.

The parents' growing reservations about the harm of treatment lead them to realise that parental consent includes considering disadvantages of, and alternatives to, treatment. Consent is not just a rubber stamp of approval. Although she will be 'more wary', Mrs Williams still sees the only course as 'to ask more questions' rather than to state her views. She seems to feel an imbalance not only of knowledge but of status. Mr Williams, a lawyer and much older than the SHO, ends up by apologising to her and hiding his anger. Jane's parents feel that relations cannot be changed into a more equal form but if tested will 'completely break down'. This challenges liberal medical ethics' assumptions about respect and veracity in doctor-patient relationships, which do not see how difficult these are to achieve. Junior doctors may begin by feeling threatened and defensive, seniors have to protect their juniors.

After writing this I went into one hospital and heard two consultants talking about a third whose work they considered to be inadequate. Three cases would have to be readmitted and the procedures repeated. They were wondering how to approach this doctor, saying how much they disliked abrasive confrontation and that this was detrimental for training junior doctors and for good working relations with staff and families. They shared Mrs Williams' dilemma of thinking that the only way to achieve better care for patients lay in risking damage to the good will on which patients' welfare partly depended. Mrs Williams was similarly constrained by her sense that nurses would feel her criticism 'like a slap in the face', so that it would be counterproductive. How could she achieve more considerate care for her child by being inconsiderate towards the nurses?

Rights and care

Gilligan shows how Kantian concepts of respect as noninterference can 'appear frightening in its potential justification of indifference and unconcern'. (1982:22) It is an incomplete

morality which needs to be complemented by the contrasting ethic of care. Gilligan also shows that subjective awareness of others through our shared humanity can be a moral strength. (1982:16) Whereas Beauchamp and Childress (1983) try to separate off a cerebral morality from our disposition, Gilligan and Wiggins see the kind of feelings described by Bion (1962) as a source of moral discernment.

'Love is tied to the activities of relationship and premised, like attachment, on the responsiveness of human connection, the ability of people to engage with one another in such a way that the needs and feelings of others come to be experienced and taken on as *part of the self*. As experiences of inequality and attachment originate moral reasoning, generating a preoccupation with justice and with care, so too the experiences structure moral feelings of shame, guilt, love and sorrow.' (Gilligan & Wiggins 1986:15)

The moral limitations of abstract rules as a protection for sick children can begin to be seen through examples like Jane's.

'The moral problem arises from conflicting responsibility rather than competing rights and requires for its resolution a mode of thinking that is contextual and narrative rather than formal and abstract. This conception of morality as concerned with the activity of care centres moral development around the understanding of responsibility and relationships, just as the concept of morality as fairness ties moral development to the understanding of rights and rules.' (Gilligan 1982:19)

Yet there is not a simple answer. Obligations to Jane, for example, are bound up with other obligations between the adults caring for her and are set within restricting hospital routines which will be discussed later.

Gilligan considers that the morality of rights emphasises separation and the individual standing alone. It perceives a dilemma as a self-contained problem in moral (or medical) logic open to the correct solution. In contrast, the morality of care sees connection and the quality of the relationship towards the sick child as primary. It sees ethical dilemmas as concerned with avoiding hurt and with a choice between evils, such as to remain silent about care which seems inadequate, or to risk damaging a relationship by criticism. The responsibility becomes 'to discern and alleviate the "real and recognisable" trouble of

this world.' (p100) An impersonal system of logic and laws cannot uncover the problem of suffering. This is revealed through communication, and contingent and psychological experience. (p29)

Respect means relooking and reknowing. Respecting care means realising children's needs through becoming involved with them and accepting that moral feelings can heighten rational awareness. Mrs Williams is embarrassed that she is 'over reacting'. Anxiety tended to be counted as negative and invalid rather than as a source of awareness. For example, a doctor voiced a typical response when he said of another mother, 'She is spectacularly over-anxious. She keeps accosting me about her child's problems.' Medical knowledge is constructed in such a way that it can discount empathy and regard feelings as an obstacle to instrumental achievement. Yet some doctors did combine care and respect, sympathy and clear judgement. A mother remembered how some years earlier a consultant had said to her:

Although he would take our views into account, the final decision about whether to operate was his. He also said some words which we will never forget. "To us Linda is a rare and fascinating case, but we will never forget that she is your precious daughter." In that light, we were happy that the decision was his and we have both always felt, and do so now that he was completely right. We have complete faith in him [] and have always felt that he sees Linda as a whole child in a family setting rather than just another interesting heart case. Before the operation, like all the others, he said what a high-risk op it was. I said, "What I want to know is, will she make it?" His reply, putting his hand on my arm and Linda's - "She'll make it." It was so unofficial but kind. Somehow I felt he was saying, "No guarantees, but ..." I wasn't led to false hope by that, but things weren't quite so black, I think. []

The time will come, I think, when we will say, "enough is enough". We are not prepared to put her through endless hopeless ops. We have enough confidence in Dr X and his knowledge of Linda, his kindness and consideration to trust his advice and his reading of possible outcomes. We trust him and I think this is essential when thinking along these lines."

Like the nurse who calmed and comforted patients the doctor offers combined technical and personal care, listening to families and making the crisis of treatment easier to endure. It helps parents to know that decisions are made not only by technical rules but also with awareness of the individual child.

By linking the phrase 'his reading of possible outcomes' with the doctor's kindness, Linda's mother implies that she thinks the personal outcome for Linda, how much she will benefit or suffer, not just technical feasibility of surgery, will be counted in decisions about surgery.

In communication, the way in which doctors interpret and apply their knowledge is as important as what they know. The wise use of bits of information depends on how the pieces fit into a framework of awareness. This understanding goes beyond rational analysis and is partly informed by experience and compassion.

The first four chapters have explained theories, methods and concepts for researching informed consent. The next four chapters consider the consent process in a broadly chronological order: the outpatient clinic; the medical meeting at which doctors plan treatment; and two chapters on the inpatient experience and discussions about consent in the wards.

CHAPTER FIVE
OUTPATIENT CLINICS

Cardiologist: What do parents want from the clinic? They want to know if their child has something wrong with the heart or not, and if so what the problem is and how we can manage it.

Mother: I don't think they realise how much you build up to the outpatient appointment. You're looking for a great deal of reassurance and information. They're not just there for medical expertise, but for a counselling role as well.
(From interviews in the cardiac units)

Observations made in outpatient clinics will be reported in this chapter, to show the use made of the forms of knowledge, discussed in chapter 4: knowledge as information or as awareness. I will argue that there are associations between the way consultants perceive their part in the tertiary care network, the way they define paediatric cardiology, the issues they discuss with families, and the type of clinics which they hold. I suggest that there are associations between each consultants' definition of paediatric cardiology and their management of consent as a process of information or of growing awareness. This suggestion will be supported by analysis on several levels. First, differing interpretations of paediatric cardiology are explained. These are then related to the tertiary care system. Thirdly, the setting and routines of the clinics are described. Fourthly the likely influences of the different types of clinics on the consent process is considered. Fifthly, a few examples of cases will show connections between the form and content of discussion and the clinic setting.

Children's heart defects are usually first noted by the obstetric team at birth, or by the primary care team (GP, clinic or school doctor). The child is then referred to the local general paediatrician (secondary care) and then if necessary on to the paediatric cardiologist (tertiary care). In 1984-86 there were nine designated paediatric cardiac surgery units for England and Wales. Patients would arrive in the two units observed, both in special authority, postgraduate teaching hospitals, from anywhere in the UK and from abroad, referred by doctors with contacts in the units or because these are the two

leading units in this country. Most patients were referred through established tertiary networks. One theme of the next section is the relation between paediatric cardiologists and other doctors in the tertiary system.

1. Interpretations of paediatric cardiology.

Differing definitions of paediatric cardiology were associated with different clinic arrangements. First, I will summarise three interpretations of paediatric cardiology to show expectations which people held about the purpose of the clinics. The interpretations also help to explain the ways in which the clinics were organised.

The family understanding of paediatric cardiology was informed by personal experience. Having a child with heart disease meant, for example, hours of trying to feed a breathless baby, or the child seeming to have almost endless coughs and colds, or a child being accepted by the local school only if her mother went in to carry her up and down stairs. If the child was asymptomatic, heart disease meant worrying about the puzzling gap between medical theory and the child's apparent wellness, wondering about possible hidden effects and whether risky treatment really was necessary. If the child was treated successfully there was great relief and pleasure in normal achievements. Families tended to want to talk in the clinics about their experience of heart disease as it affected the physical and mental health of the child and family.

Medical definitions of paediatric cardiology were informed mainly by theoretical, generalised knowledge. Symptoms were relevant in so far as they contributed to the diagnosis and assessment necessary for managing heart disease. However, medical definitions covered a range from those emphasising paediatrics to those emphasising cardiology.

Towards the paediatric end of the spectrum, doctors encouraged families to discuss a wide range of problems related to heart disease, beginning with feeding and weight, chest infections, activity, and going on to how the child's education, achievement and mobility might be affected by the heart condition and treatment. Some adolescents became concerned about social

consequences of congenital heart disease as it affected personal identity, career prospects, contraception, pregnancy, and so on.

The paediatric cardiologist is in a unique position to collect and distribute practical knowledge about caring for children with heart defects and to correct misinformation from people without this specialised knowledge. For example:

Mother: It's absolute agony feeding him, trying to get it in. He pants so much. Our GP said he must have his 5oz.

Consultant: Most babies with heart problems feed poorly. 5oz is not desperately important.

M: [Seeming very surprised and relieved] Oh, that's a relief.

C: We may have to accept he's not going to have the 5oz... Get in as much as you can. You could try a teat with three holes. Many mums find this helps.

F: Now he's got Boots' largest hole.

C: Yes, okay, see how it goes. Three may be too strong. He may choke but you could try it. And try going on to solids. It's a bit early but sucking is very hard work for him. []

M: We've kept a weight chart and a record of every feed over the last week and his weight gain is just below the lowest percentile.

C: Dr R [paediatrician] and I will keep an eye on him. The weight gain is encouraging. We'll give him three sorts of medicine to help his heart muscle pump better and to pass more wee because his lungs are heavy and wet. It'll drop his weight a bit to lose water, but we'll try it and see how he gets on.

M: Try it, yes.

And the discussion continued slowly at the parents' pace in response to their concerns, the doctor listening to and learning from parents (as with feeding methods), and interpreting the treatment in everyday terms of how they would experience it, such as the possible weight loss which could cause extra anxiety, unless explained, when the parents were already clearly worried about weight.

The two units offered numerous examples of feeding problems: some babies needed to gain weight in order to be fit for surgery but the heart defect prevented them from gaining weight; the effects of surgery and of drugs could cause nausea, anorexia, and weight loss which were frequently associated with family distress and disharmony; discharge was delayed if children were not eating well, yet parents felt, and were often proved correct, that the child would not eat well until back at home; ventilator tubes

made throats sore; after long periods on a ventilator, babies lost the ability to suck; and so on. Feeding is just one of the medical-social issues closely related to paediatric cardiology. One mother described her problems when they were separated.

'I feel I've been left alone and in the dark. He's still tube fed after six months. I try him with tastes but he breathes in sharply and chokes. I worry because I've seen babies in here with pneumonia from inhaling food. I think it's all connected, feeding and breathing problems caused by complications after heart surgery. So many babies here have it, yet they seem to treat it as though it was uncommon. I was surprised when my health visitor said try a speech therapist, but when I told the consultant, he said, "A very good idea, they can be a great help with feeding problems." So why don't they have a speech therapist here, or at least advise us to find one?'

As well as sharing practical concerns, the paediatric based approach acknowledged shared feeling such as anxiety. In the following example, the consultant advised high-risk surgery for a child who had nearly died after his previous operation.

'We [cardiologists and surgeons] spent ages trying to go through everything. Naturally we had a large attack of cold feet. [] I think we should face what we faced before. We'll have a large cup of coffee first, but it's something we should get on with.'

The next operation did prove fatal and the parents felt that the consultant's expressed concern was an immense help to them. Part of the consultant's interest in sharing knowledge with families is shown in the way he started an association for families of heart children to enable them to inform and help one another; he also publishes articles explaining heart defects and treatment to parents. The difficulties of this approach are that it is time-consuming, it can only be done in clinics with short lists, and explicitly sharing concern with families can be oppressively sad, for doctors seeing so many difficult cases. One solution in large clinics with many observing doctors could be to use them partly as a resource, using their time to talk with and listen to families, to sort out misunderstandings and to report information gained about the child back to the cardiac team.

The definition emphasising cardiology assumed a concept of medical information as expert, scientific, technical, possessed

by doctors and transmitted to families. The purpose of the clinic, in the words of one cardiologist was:

'to assess, diagnose and manage congenital heart disease, or to rule it out. You must give a definitive statement, as far as you have the information to do so. A tertiary referral centre is the end of the line for expertise in technical aspects of making an accurate diagnosis. It is a matter of appropriate use of time.'

To save time, general matters such as feeding were expected to be left to paediatricians and nurses. Cardiac treatment was seen as inseparable from generating medical knowledge in order to raise standards generally, through learning, teaching and research, trying new techniques, and assessing effects of interventions through follow up studies and continuity of care. These aims were achieved when a few consultants saw many cases, quickly, in long busy clinics also used to teach groups of junior doctors. There was little time to translate medical terms, such as a prescription for diuretics, into family terms of how the drug would affect the child. Doctors needed firm control over the clinic agenda. One consultant said:

'It helps if the parents can hold themselves back and give a clear history, give a clear answer to a clear question, in my order not theirs, not to rush in with all their anxieties together, and then at the end the doctor says, "Any questions?" and they come up with the extras. I think the physical examination, the objective clinical data, is even more important than the history. The parents' history isn't so important to me; some are good witnesses and some are vague and not terribly helpful. When you don't know the family and you're making all sorts of observations and decisions about surgery...'

This doctor showed the difficulty of basing vital decisions on the evidence of anxious strangers, and the importance of thinking clearly and systematically on clear evidence, abstracted from the 'extras'. Clinical expertise and compassionate discussion with families were clearly apparent in both kind of clinics. Each doctor used a range of paediatric and cardiac emphases. Yet they had to choose between the two emphases, both of which had very important benefits, and to allocate time mainly either to talking with families or to teaching and research.

Doctors emphasising cardiology were mainly concerned with

knowledge as the discrete package form of information. Parents were informed of technical data and decisions. In this approach, anxiety was liable to be perceived as an obstacle to efficient thought and action. On the other hand, doctors emphasising paediatrics tended to interpret medical and family knowledge as awareness. They related cardiac theoretical knowledge to the experience of the family, such as difficulty with feeding a baby or accepting risky surgery. The doctors acknowledged causes which gave sense and rational meaning to anxieties so that these feelings could be accepted as part of the cardiac paradigm. Parents' concerns could be classed as knowledge central to cardiac care instead of as extras. When parents were perceived as knowledgeable, and able to initiate topics and contribute information, they became more equal partners in discussion.

Combining information and awareness in this way can have implications for both the informed and voluntary aspects of consent. Families are liable to be more thoroughly informed and prepared for the experience of surgery, such as what intensive care will be like for the child. Information goes beyond technical accounts of how a hole will be patched or a tube reconnected. Parents views may be taken into account in medical decisions. However, the cardiac approach tended to expect families to consent to an expert medical proposal, based on clear medical criteria, with reluctance to lose the clarity, and perhaps the scientific integrity, of decision making by too much involvement with social contingencies. In both units decision making was influenced mainly by the cardiac approach since consultants mediated between parents and the decision making teams as discussed in chapter six.

2. Clinic arrangements in the tertiary system

The two hospitals tended to emphasise different aspects of paediatric cardiology in their clinic arrangements. At CH more interest was shown in the whole child; for example, cardiologists might discuss non-cardiac problems in their patients, and admit

CH = children's hospital HH = heart hospital

children with chest infections, believing that all the care should be centred in one unit which families know and trust. Some also considered that cardiologists' time was best spent in directly caring for the child, rather than teaching and trying to share care with numerous referring doctors. CH specialises in treating children with multiple congenital defects, so doctors there are used to taking several medical problems into account.

In contrast, HH clinics were firmly set in a tertiary care system, and based on the following beliefs. Local paediatricians and GPs provided the best all round care. All noncardiac problems, such as feeding, should be referred back to them. Children should be admitted to the cardiac unit as briefly as possible and only for care which could not be provided locally. Regular reports and contact between the referring and central hospitals ensured good continuity of care. Joint cardiac clinics should be held in the referring hospitals, partly in order to teach paediatricians cardiac care methods. This enabled them to diagnose and treat children early so that they arrived at the cardiac unit in as fit a condition as possible. Tertiary centres were intended to concentrate on teaching, research and developing medical knowledge.

There were many social and economic, as well as medical, advantages for families when care was provided locally if possible. A disadvantage was the divided care and the doctors' attempts to separate off psycho-social and physical problems which they thought were 'non-cardiac' but which families saw as related and inseparable. HH cardiologists tended to stop parents from referring to 'non-cardiac' problems and advised them to talk to their paediatrician or GP. Greater interest at CH in 'noncardiac' issues, was associated with less interest in delegating and sharing care with paediatricians and in holding joint clinics. The different emphases in the two units are shown in tables 1, 2.

Table 1 Paediatric cardiac outpatient records

	<u>Children's Hospital</u>	<u>Heart Hospital</u>
	Oct 83 - Sept 84	Jan-Dec 84
<u>At the central unit</u>		
Total cardiac cases seen	2800	1529
New cases	484	465
<u>At joint clinics in referring hospitals</u>		
Total cardiac cases seen	526	1026
New cases	-	326
<u>Total number of outpatient cases</u>		
	3326	2555

Source: Hospitals' records departments.

CH had six cardiologists, roughly averaging 525 cases each, although case loads varied and children were shared between consultants. Visiting research doctors and junior doctors also took clinics. The emphasis seemed to be on offering families medical time to discuss a range of problems. Joint clinics were held in eight hospitals.

HH had two cardiologists and one part time consultant near retirement who saw a few children, but the average for the full time consultants was well over 1,000 cases. Visiting and junior doctors were taught in the clinics and sometimes junior doctors took clinics but, on the whole, other doctors added to the consultants' teaching load rather than helping to share the clinical work. By offering families briefer sessions which concentrated more narrowly on cardiac problems, it was possible to provide continuity of experienced consultant care. Joint clinics were held in 21 hospitals.

My survey What the parents think (attached) also shows the emphasis at HH on sharing care in the tertiary system when the replies are separated into the two hospitals.

Table 2 Parents' estimates of their child's attendance at outpatient heart clinics.

	<u>CH</u>	<u>HH</u>
Total of returned questionnaires	117	161
mean attendance per child at central hospital clinics	5.6	1.9
mean attendance per child at joint clinics	4.9	8.7
mean total attendance per child at central and joint clinics	10.7	10.6

The parents' estimates of the cost and time for families of attending clinics (What the parents think p5) indicate some of the pressures on families attending, especially the central clinics, and the benefit to them of the joint clinics.

The pattern of inpatient care reflects the pattern of outpatient care in the parents' estimates in my survey. More local clinics are associated with more admissions to local units.

Having summarised the clinic organisation in the tertiary care system, I will describe aspects of the form and content of clinics held at the central hospitals, and continue to consider associations between definitions of paediatric cardiology and ways in which clinics were managed by different cardiologists.

3. The setting and routine of the clinics

I mainly observed four consultants, two in each hospital. This section describes the clinic setting and routines which seemed to encourage (give heart to) or restrict parents' participation in the clinics. Most details are described because their opposite was observed in other clinics where families reacted in a different way. This is not an exhaustive classification of characteristics, or a description of a particular doctor's style since the doctors tended each to use a mixture of styles, although with an overall emphasis which might be called either paediatric (concern for the whole child) or cardiac (concern for cardiac expertise).

Clinics which encouraged family participation had pictures, mobiles and toys in every room. Most of the staff had chosen to work with children and received special training for this. One

staff nurse told me how she tried to welcome every new family and explain the clinic to them. She enjoyed getting to know the regular patients. Playworkers managed the clinic playroom and ensured that a box of carefully chosen and maintained *quiet* toys and books, to appeal to a range of ages, was kept in every consulting room. The emphasis was on helping children to feel less intimidated and anxious. Their attention was distracted during investigations with talk about pictures and toys. When the child played quietly adults were able to talk.

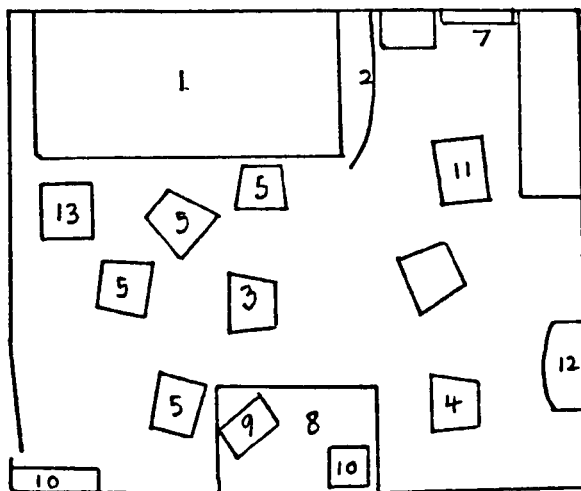
The doctors would invite the family into the consulting room, including friends who could play an important part in the clinic. By talking more emphatically about the child's weakness or the parents' worry than the parents felt able to do, friends sometimes gave the doctor a clearer understanding of the family. (If a nurse called in the family, often other visitors would be left outside and she acted as a kind of barrier.) Consultants introduced themselves at the first meeting. They sat talking with the family in a small close group away from the desk, (see plan), looking directly at them not at notes or xrays. Henley (1977) has shown a correlation between personal time and space. The more time people have for one another, the closer they tend to sit; they also look at one another and talk together more. In contrast, in busy clinics doctors increased the pace both by attending to work (reading and dictating notes, examining data) and thereby reducing personal contact which slows down the pace. In encouraging clinics, the door was closed signifying that a certain medical time and space and attention was allocated for the particular family, by the consultant. The onus was not on parents to ask for time as if taking it from other families.

Children sat on adult size chairs on a level with adults and therefore tended to be included in the conversation. Children would talk, laugh and protest much more when treated with respect and doctors would respond with more comments of interest, sympathy and reassurance. For example, the four year old who bounced into the room saying, 'I've got a mixer in my mouth and all I can say is Mmmmmmm,' was asked by the consultant what drugs she was on and was treated rather as an adult patient. A tense adolescent was shown how to relax during examination.

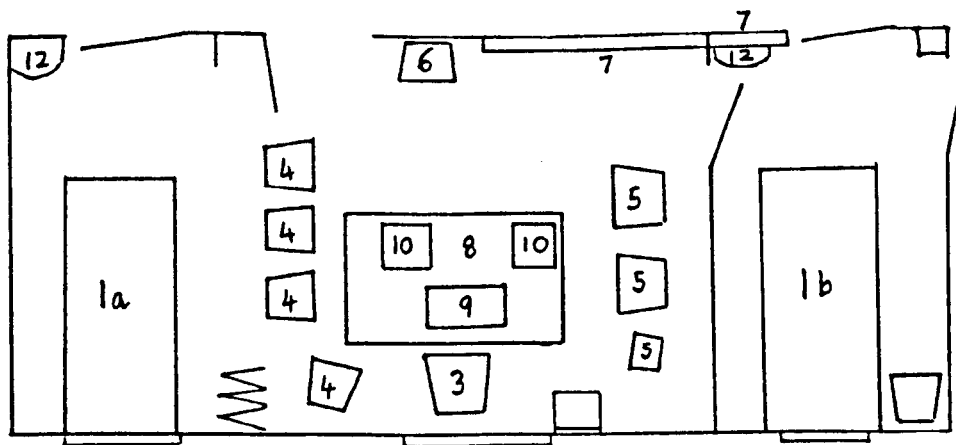
Figure 1. Plan of two clinic settings

Layout A encourages close contact between the consultant and one family. Layout B enables groups of doctors to work quickly with over-lapping pairs of patients.

Layout A



Layout B



- | | |
|-----------------------|--------------------------|
| 1 couch | 8 desk |
| 2 curtain | 9 patient's notes |
| 3 consultant | 10 other patients' notes |
| 4 observers | 11 toy box |
| 5 family | 12 basin |
| 6 nurse | 13 echo machine |
| 7 xray viewing screen | |

Parents would lean on the desk, it was not used as a barrier or a symbol of authority. They would put bags and bottles on it and look at the notes. Often at an angle across the corner of the desk the notes could be read equally by doctor and parent. The consultant would have read the notes before meeting the family. The consultant might talk about a general topic first, such as a holiday, before narrowing down to medical issues. Although early discussion often produced items for the medical notes, the child's daily life was treated as a topic of interest in itself. For example, a consultant considered that Emma, aged five was a 'terribly anxious child' and greeted her with:

D: Where's my Christmas card? I thought you were going to draw me one.

[They talk about Christmas and then about school and the child vivaciously imitates her teachers, incidentally giving evidence of a good post-operative recovery.]

D: Can I listen to you?

Emma: No.

Father: But we came all this way, we got up at 5.30 in the dark!

D: We'll start with the pulses. Do you remember about them?

E: Yes. [Gently resists at first.]

D: Now I'm only going to press your tummy.

E: Uurgh, it's cold.

D: Shhhh. The baby before you was good. You'll have to be quiet.

E: Uurgh, it *does* hurt, really. [She hovers between laughing and crying]

D: Do you remember about taking giant breaths? []

E: We've had no more problems about nausea now that she's on new drugs. [] The school's very pleased, she's more independent now, they say she's a different girl.

E: [Sounding frightened] I'm not a different girl.

D: Well, not exactly.

Mother: No, it's words people use. [She explains. Emma whispers] Can she have crisps, with salt?

D: Yes.

[Everyone is pleased, as if this 'proves Emma is well again'; she cries with excitement.]

Among the advantages of encouraging children to talk are that a clearer picture can be obtained of the child's quality of life, of discomfort such as nausea (which may be caused and/or cured by medical treatment), and of anxiety. A question about crisps, which could seem trivial, was perhaps central to Emma's understanding of herself as fully recovered after major surgery

and as not a 'different girl' but her former restored self. Detailed discussion enables the doctor to know more precisely what are the salient issues to the patient and what practical help and reassurance are required. A disadvantage is the amount of time required not only to talk but also to persuade children to cooperate with medical procedures. Friendly informality both allows children to express their fear and dislike of procedures, and also responds with respect and persuasion instead of attempting to save time through force or by ignoring anxiety. Psychologists provide numerous examples to show that children benefit when they are not too afraid to protest but can express anxiety and receive explanations and reassurance. (Petrillo & Sanger 1978)

During examination, clothes might be just unbuttoned or rolled up, not always removed. Children were undressed as briefly as possible and always fully redressed before leaving the room. Small children sat or lay on their parent's knees to be examined. If they were asked to go on the couch this would be for a short time unless they were echoed.* Parents generally sat near the head of the couch. There were pictures and mobiles, walls on two sides of the couch and a curtain at the foot, so that the child need not feel too exposed. (In other clinics doctors stood round three sides of the couch under bright lights, not seeming to notice the fear and embarrassment shown by all ages of children under the gaze of strangers.)

If one or two medical observers were present, they were introduced and, if the child seemed calm, permission was requested for visiting doctors to examine the child. They would establish eye contact and talk reassuringly, learning relational as well as technical skills. These observers were used to help children by playing and talking with them or by taking older ones for an ECG so that the adults could discuss serious risks more frankly and then decide how to inform the child. The consultant would sit talking with the family (not impatiently holding the door handle) until issues appeared to have been clearly understood and agreed, and then might shake hands with them and would show the family out. Strong (1976) has noted how behaviour in clinics, such as ignoring questions, is accepted in doctors

but would be unacceptable in patients. Some clinics reduced disparities between medical and patient behaviour, doctors were more attentive, and patients more assertive when they were treated with respect.

Participation tended to be encouraged in CH clinics, less so at HH where the authorities were concerned about problems and commissioned two nursing reviews of the clinics. The reviews reported that patients had to wait for very long periods and

'became agitated when waiting and at times very angry [] The nurses are subjected to a considerable amount of hostile criticism amounting at times to verbal abuse, as they are unable to offer any solution to the patients' problems, this is particularly difficult for the nurses to accept.

Nurses are responsible for creating a comfortable environment [] and an efficient system [] ensuring that [patients'] physical needs are met and giving appropriate information [] about investigations, treatments and future appointments []. Basic nursing skills include [] developing a rapport with patients.' (O'Connor 1985:6,35-6)

However, the report added that nurses 'lack the opportunity to carry out' these skills. (p36) This was a recurrent theme in the clinics and wards: nurses' awareness of patients' needs and frustration that they were unable to answer them, partly because of unwieldy hospital customs.

The central theme of the second report was the need

'to educate staff to be more aware of the emotional needs of [child] patients. [] A negative and traumatic experience can mean that the child responds with fear in childhood and avoidance in adulthood. The pattern set in these formative years can greatly influence the growing child whose condition is likely to require life-long monitoring.' (Seager:1986)

For example, the parents described to me the difficulties for children from each age group having xrays. The babies were floppy and had to be held in uncomfortable positions. It was important to have clear xrays of children in correct positions and the technical standard of investigations was thought by the doctors to be high, but the treatment of the children caused problems. When a doctor asked why one three year old child was crying, his mother replied 'He doesn't like doctors, or his mother, for putting him through this... He was screaming his

heart out at the xray and ECG.' Later she said to me, 'I can't get over what is happening to this little young man. This is the worst thing - when he cries so much for the tests,' more than his repeated admissions for surgery. The mother of an 8 year old who had been to many clinics said, 'She screamed a little. When the technician said, "They all do," I thought, if only you could explain, it would only take a few seconds, but they just make them scream.' Gill (1986) criticises her colleagues, not trained in paediatrics, for commonly causing unnecessary distress to children in xray departments.

Children's nurses at HH criticised other staff for not being paediatric orientated. None of the clinic nurses were trained children's nurses (RSCNs) and some told me that they disliked the hassle and noise of children's clinics. Crying in the waiting area could often be overheard in consulting rooms. At one clinic a series of distressed children arrived to see the doctor seeming to be further upset by screams from the weighing room next room. The consultant said, 'Oh, you are a misery', as they failed to calm one baby. He looked towards the weighing room and added, 'That's a loud noise. It sounds like a murder.' He asked the mother to return to another clinic as the baby continued to cry so loudly that the heart sounds could not be heard. Later I asked the nurse why a child was crying so much and she said, 'I've just weighed him. He's been in recently - got a big red scar. I got a child yesterday, just to take a tiny stitch out and he yelled the place down - blasted my ears out.' This was an unusually noisy clinic and in over two years I saw only four children who cried too much to be examined (all at HH). Yet there was often crying in this clinic and no one seemed to feel responsible for considering the cause of this distress and whether some might be prevented. Only the parents saw the cumulative effect on the child of a series of investigations, often ending with being examined by a row of observing doctors. I never saw a parent ask them to stop despite cases of obvious distress.

Seager concluded that clinic staff

'are failing to offer positive emotional support and can make visits difficult and unpleasant for the child and family. [] It requires both time and effort to create

rapport with the families, and it is essential if a caring and trusting relationship is to develop between the patients and hospital staff.' (1986)

She recommended that children's nursing and play staff be appointed as well as an RSCN cardio-thoracic clinical nurse specialist to ensure: that parents understand the medical information; to talk over questions parents may have before and after seeing the doctors; to be aware of the overall experience of children through the whole clinics; through contact with inpatients, to 'provide a strong foundation for parental support during critical illness and bereavement.' Seager stressed three related qualities which I found were vitally important in the wards and clinics: nurses' training, personality and their ability to influence hospital routines. As an observer I saw many ways that the clinic could be changed to relieve the stress on families and doctors. The nurse could draw together medical and family knowledge and work with an enlarged team, involve a dietician, social worker and other help more fully.

One approach to reassuring patients is to impress them with professional and technical excellence, with obviously expert, competent care. A contrasting approach is to create a friendly, relaxing, homely atmosphere in order to help people feel at ease, able to talk about their anxiety and seek direct reassurance. The first way stresses formality, and tends to emphasise the distance between skilful staff and dependent patients; the second stresses informality and tries to draw patients and staff together on closer levels of equality and intimacy. Both approaches concern excellent care, but differ in the ways in which the staff convey to patients their confidence in the quality of care; overtly with serious formality or implicitly with friendly informality. Individual staff combine both formal and informal approaches, yet details can combine to create an overall emphasis. CH tended to be informal as a way of overcoming children's anxiety and resistance. The HH design and attitudes tended towards formality.

Talk about the child's daily life at HH tended to be omitted or restricted to medical aspects and specific answers to doctors' questions. For example:

Doctor: How old is he now?

Father: Er, over four.

D: Can you slip his top off? [Checks notes.] Yes four and a half. And how do you find him?

E: Er, he's much better.

D: He goes to school?

E: Yes.

D: Can he manage a full day at school?

E: Yes. He goes half day.

D: That's because of his age?

E: Yes, he's starting full day in September.

D: Right. Does he get many chest infections?

[To child] Hullo, stand up.

[Starts to examine child.]

When doctors tended to ask closed questions requiring precise answers, such as whether the child could physically manage a full day at school, a discussion format was set up which implied that other answers were irrelevant or incorrect. This restricted the family's comments and questions in many ways. By checking the notes the doctor (probably unintentionally) implied more respect for medical notes than for parents' reports. This father had waited 2½ hours, again the implication being that medical time was more important than his own.

Parents spoke of the difficulty of interrupting the medical flow when a group of doctors were being taught. One mother expressed a common view.

'You don't get the attention you need. You can feel quite flattened if you go out and you haven't been able to ask the questions you wanted to. And if you do ask, they sort of get away with it and dismiss it.'

When families explained their main concerns in their own terms, as Emma did, this could involve revealing doubt, ignorance, fear or discomfort and asking for reassurance. People were less likely to reveal this kind of vulnerability in a busy, impersonal crowd.

HH consultations tended not to be a continuous whole from the family's point of view. There was no obvious person, such as a children's nurse, to help, as the following example suggests. The chair at the head of the second couch was fully used as the only place for families to put clothes and bags, as well as the only place a parent could sit to wait, to comfort the child and to be

facing the examining doctor who always worked towards the window. During two consecutive clinics I observed parents of ten patients in turn stand throughout their consultation by the doors, holding their bags, behind the doctors and therefore blocked off from the child and the medical conversations. The reason for the change was that the guage which measures blood pressure was left on the chair. None of the staff seemed to notice the box or how it influenced the consultations and these families seemed not to have the confidence to move it or even to ask for permission to do so. If families felt intimidated in very small matters, how confident would they feel about questioning more important issues such as treatment decisions?

Observing doctors each in turn reported conditions and sometimes treatments which they suspected to be correct and finally the consultant would tell them the actual condition and treatment and then turn to talk to the parents. This teaching method had the advantage that parents were able to hear much about the heart condition and had time to think about their questions. Yet some parents and children found the medical talk of their own and other cases confusing and alarming. Some appeared to be uncertain whether to show interest or to seem not to be eavesdropping; the unusual position of being a central topic of conversation while being ignored can be difficult to manage. They were left in mounting suspense, sometimes hearing unfounded suggestions, like the mother whose first baby had died of a heart defect and her second had had heart surgery. The doctors standing talking behind her, talking about her third baby, did not see her crying; she turned very white and could not stand when finally told that her third daughter's heart was normal. Families coming to terms with the shock of realising that the child has a heart condition, or worrying that more surgery may be due, heard their profound individual experience discussed in impersonal terms of syndromes and percentage risks.

The use of technology could heighten anxiety. For example, one mother brought three small children to be examined after her eldest child had suddenly died because of a ruptured aneurism on her heart. The whole family was very disturbed; a visit to hospital was associated with the child's recent death in

hospital. Several doctors carefully examined the children and decided to echo them, partly as a further check, partly to give added reassurance. The family waited until mid-afternoon in a dark, narrow corridor outside the echo room with its chained and padlocked door, and with nothing to occupy the restless, noisy, hungry children. I waited for two hours with them, as the mother talked about the lack of care and consideration that she felt her daughter had received. She spoke of confusing advice from doctors about whether or not to have echoes or catheterisations* for her other children. In her bewilderment and distress, she seemed to need someone who could listen to her for a long time, before she could return to a mental state capable of accepting medical information. The family seemed so frightened by the technology and seeming lack of care as to be incapable of accepting overt messages of reassurance.

4. Relation between the clinic types and informed consent

Examples of contrasting clinic practices have been selected in order to show how they appear to be associated with the form and content of discussion between doctors and families. A leisurely, quiet, sympathetic consultation, demonstrating concern for the child as a person implicitly and explicitly through clinic practices is likely to encourage families to talk about their concerns and to gain growing awareness. Patients can help doctors to provide the information families need, in a form they can understand. Patients who feel able to question and interrupt can slow down the flow of information to a pace at which they can assimilate and respond to it. One father said,

'Although they make an attempt to explain in lay terms - but then they start using medical terms - like 'constriction', 'ligation', 'granulation of the wound'. If they use one word you're a little unsure about, your mind pauses at that one. You reflect. You try and work out what that one means. They gallop on at a racy pace and you miss the next part. If they slow down to draw, you can keep up with them.'

Doctors concerned with paediatric aspects of care showed much interest in informing parents with diagrams and coloured sheets, so that from explanation they could quickly progress to

discussion. Without visual aids, verbal explanations of visual concepts could be very confusing. For example:

Doctor: And there's a thickening of the valve.
Mother: Oh, I thought it was a narrowing.
Doctor: Well, that's the same thing.

One mother described the effect of the doctor's pace and manner on her ability to comprehend.

'I don't feel daft when I ask Dr X a question. He seems to realise you don't understand at first but he doesn't mind repeating at all. He has that nice nature, whereas with Dr Y, I said, "Yes, I understand," so that I wouldn't look a fool, although I only understood a bit. When you're worried it goes in one ear and out the other, unless it's me. I am thick. Dr Y said to ask as much as I like but sometimes it's his attitude, always seeming busy, rush, rush, rush. He spoke very fast. I think it's not what they say but the way they say it. If they seem nice and relaxed you can take in more. You've got time to think. If they speak slowly to you they seem as if they're more concerned.'

Consent within the fuller discussion in paediatric based clinics is liable to be more informed and also more voluntary, because causes of unwillingness such as misunderstanding or a specific fear can be addressed. Parents in these clinics expressed more reservations about the risks of surgery and tended to question the need for it instead of quietly accepting information. Entirely voluntary, free and eager consent to heart surgery is impossible; the experience is not pleasant and patients are already under duress from the dangers of their condition. Voluntariness in relation to surgery is a relative concept. Yet it is a state in which the patients (or parents) can choose that agreeing to surgery is preferable to refusing it. It is also a state of being conscious of unavoidable duress exerted by the nature of the illness or defect but not of avoidable duress, such as from hospital staff. Voluntariness is encouraged by informed and sympathetic persuasion rather than coercion, by allowing the patient to protest and resist and by responding with respect and concern. Partly by questioning and protesting, Emma was able to use the doctor's knowledge as a resource and to obtain practical help for her nausea and for her anxiety about her condition, treatment, diet, and perhaps her

self-identity generally, as well as her dignity as a patient.

Consultants' use of clinic time and resources seemed to be strongly influenced by their beliefs about the best means of practising paediatric cardiology, whether to put most emphasis on cardiac expertise or on communication with families. Both activities were highly valued and they are not wholly separable, but when these concerns competed for time, doctors' priorities became apparent. Consultants' priorities seemed to influence their selection of the form and content of the information discussed, and the degree to which they considered it expedient to keep to technical information or to share personal awareness with families.

5. Outpatient clinic examples of encounters

Extracts of transcripts of clinic sessions will now be used to give examples of kinds of information exchanged and some of the ways in which the process of achieving informed consent becomes easier or more complicated. Clinics with an emphasis on cardiology might be expected to give more standard information, than wider ranging paediatric based clinics. Yet even in cardiac based clinics, parents were informed about similar operations in widely varying ways. The examples are all from one cardiac centred clinic, partly to indicate the range of cases and the pressure to work quickly. The clinic had 14 patients, an average number for this doctor's clinics. As it is only possible to look in detail at a few out of hundreds of patients, I have used the case study method of using examples to show how they illustrate themes in the consent process.

Literature about consent often implies that it is possible for doctors to give patients standard information in systematic stages. This clinic illustrates difficulties in achieving this. Each family's responses varied, and the consent process was fragmented. Children might attend many clinics with different facets of the case discussed each time. No one could ensure that parents understood and recalled each stage, so doctors tended to rely on parents to indicate what they wanted to know by asking questions.

A consultant who read this chapter in draft said that it

expected too much of the clinic. Parents could be more fully informed and asked for their consent later, when doctors had more precise information. A usual pattern of non-emergency treatment was: clinic, admission for catheterisation*, medical meeting about the data leading to a firm decision about surgery, admission for surgery. There were many other issues for the consultant to attend to and one person could not take on all the responsibility for informing and discussing the many serious problems with families. Yet by the time a child was admitted for surgery, parents tended to feel that it was too late to demur, also that they had wanted information earlier to help to prepare the family for surgery. Sometimes they had weeks or months to wait and wonder before admission. Later chapters show that gaps in information were not routinely filled. The clinic might also be the only time at HH when parents talked with a consultant before surgery. Someone knowledgeable, such as a cardio-thoracic children's nurse or a junior doctor, for families to talk with could greatly help the families and reduce the consultant's work.

This account of a clinic is about people attempting impossibly hard decisions, often within unavoidably adverse circumstances. It is very difficult to write about such problems without implying criticism which I do not intend, since I felt that everyone was striving to do their best for the children. Clarifying some of the problems may be helpful. The five cases in the clinic will now be reviewed.

1 Joseph 3 years, first clinic patient, 10.55-11.25am

Atrioventricular septal defect,* tetralogy of Fallot,* and Down's syndrome.

Joseph came for a postoperative check three weeks after his emergency shunt* operation. Before surgery, he had collapsed at home because of lack of oxygen, and had suffered brain damage. During an interview in the ward, his mother told me that she trusted the consultant's advice about heart surgery:

'He advised that if it could be corrected simply and would improve his day-to-day life one would obviously have it done, but one wouldn't necessarily go into open-heart surgery straight away.[] I understood the point he was making and I dreaded coming down to a moral decision of whether to treat a child because of a [mental] handicap so I

didn't think about it. I don't know how my husband felt. I felt if a decision had to be made I would leave it to him. [] We never ask about what might happen - we thought when the time came they'd tell us the possibilities.[] The consultants both told us that knowing the future was a matter of seeing visit by visit.'

Joseph's mother was most concerned about improving the quality of his present life. From what she told me, her main concern in the clinic was likely to be: to learn how to prevent another sudden collapse; and to ask about, but not try to influence, decisions about further surgery. She asked what correcting the defects would involve.

Doctor: It's an enormously complicated process to put a patch in to close those holes. It is so difficult that one sometimes wonders whether a shunt as he has had, and another one on the other side at a later date if necessary, might not be a better option than total correction. And one's not obliged to do that in view of the - um ...

Mother: Does corrective surgery sort it out - if it's successful?

D: Well it sorts out his heart, if his heart is his main problem.

M: Mm. If it's successful, usually is it?

D: Well ... you may not get perfect anatomical results. You often don't, even when the child survives because with one big common valve, you have to make two out of it ...

M: Yes?

D: [Explains about making new valves, then adds] It's still not a normal valve [] The problem is that sometimes the valve leaks a bit then you have to start trying to prevent the leak and there may not be enough actual valve to give you a perfect result. You may get a very good result, maybe... [] Against all that background one wonders... I mean one can go on for 30 or 40 years having shunts if they are good and work.

Joseph's mother, Mrs Rodin, then asked about life expectancy, and the doctor replied with several qualifications that with shunts, 'his life expectancy isn't badly affected. [] It's not going to be much worse because we don't ...' Again he paused as if not wishing to go into further detail unless asked to. Mrs Rodin moved back from the future to the present with several questions about how she should care for Joseph at home.

This example illustrates the problems of dealing with masses of information which, inevitably in the limited time of the clinic, like icebergs, remain largely submerged. Only the tips

are seen in hints and allusions. How surgery decisions will affect the length and quality of Joseph's life, what is an acceptable level of mortality and morbidity risk now and in the future, each issue involves numerous facts and opinions which are only hinted at. For example, 'if his heart is his main problem' suggests a comparison of the relative disadvantages of Down's syndrome and heart defects but this is not developed.

There are several possible reasons why issues were not explored. There were the effects of clinic organisation described earlier. This clinic was only one of many opportunities for Joseph's mother to talk with doctors. Another reason was concern with the present. Parents frequently spoke of taking one day at a time, having enough to cope with now without thinking about the future, fearing and putting off bad news, and so on. When the doctor replied about life span, 'It's not going to be so much worse because we don't ...' instead of asking 'much worse than what?' Mrs Rodin immediately returned to the present symptoms. Parents wanted a well child with as little treatment as possible; they consented to surgery when the child was clearly ill or when doctors convinced them with clear and emphatic warning that surgery was necessary, but they were unlikely to request it otherwise.

A second reason which could enable yet limit discussion was 'obligations'. Adults in the units seemed to think they had a duty to raise certain issues in fairness to the child but not necessarily to develop them. They ticked off a list of topics as a way of fulfilling obligations, if only to be able to dismiss the topic because no response could be taken as understanding and agreement. For example, the consultant paused during several remarks: 'one's not obliged to do that in view of ...'; life expectancy would not be 'much worse because we don't ...'; but he was not directly asked to finish them. Whereas when he said, 'you have to make two valves ...', Mrs Rodin prompted 'yes?' and he continued to explain.

Obviously most conversations are channelled by these kinds of cues and checks to filter out undue elaboration. The process was complicated in the clinics if parents held back questions in order to avoid looking ignorant or seeming to take too much time.

For example, one mother agreed to proposed treatment with, 'That's great'. Because she had looked puzzled, when the doctors left I asked her what she had understood and she replied, 'I haven't a clue, fill me in.'

The doctor waited each time for Joseph's mother to initiate topics and in replying he selected answers to reassure her about the condition and thereby to warn her against surgery: a sudden attack was unlikely, the shunt was working well and should prevent problems, and so on. The doctor did not mention precise ages of life expectancy. He hinted that the risk was high, ('even if the child survives'), without giving a specific risk, but at the same time he steered a balance between suggesting that the task was difficult yet not impossible for the surgeon. As in later examples, the child's relative good health is emphasised as reducing the need to operate. The current limitations of surgery tend to be presented in ways which stress high aims, difficult achievements and perfectionism: 'you may get a very good result' although maybe not a 'perfect' one. There is a careful balance between discouraging requests for surgery and sustaining confidence generally in surgical excellence.

Some parents were uncertain how much they ought to know. As one mother said,

'The doctors haven't talked to us so much this time. I think they think we should know it all by now. I feel I know all I want to for myself but, er, whether I should know more I - I don't think it's down to me to know exactly what artery goes where and - in one sense you need to know enough not to be unnerved about it but you don't need to know more than is absolutely necessary. Some people do, some don't, we're all different.'

Whereas the mother implied her duty to know, a father who was a solicitor talked about the doctors' duty to inform. Although starting with the difficulty of free discussion in unequal relationships, he implied that doctors should assess parents' competence and avoid confusing them.

'Getting the answers you require in hospital is difficult. [] You are subject to rules and regulations and methods of behaviour and an environment which are entirely unfamiliar, so you feel disquiet, disorientated, you never feel on an equal footing with doctors. [] They are very forthcoming here about what they are going to do. [] What you want to

know really is: What is the problem? What's the diagnosis? What's the remedy? What are the chances compared with other surgical procedures? What are the chances of success, the chances of remedying the defect? What are the risks attendant on it? How serious is the defect? What would be the consequences if it wasn't remedied? And then any reasonable person can make a judgement taking the risk against the benefit.

In my son's case there's no problem. He would have died if he hadn't had surgery, so whatever the risk it was worth having a crack. I don't think you want to know about the techniques they use or the plastic tubing or whatever it is, because that's just mechanics.

I think they have an obligation to give you sufficient detail to enable you to understand. [] Not because it would make you withhold consent, but I think it helps you to prepare yourself for the possibility of harm. [] I suppose there is a point at which the risk is so slight you wouldn't need to know, I'm not sure whether two in a thousand is sufficiently small. It's difficult, you have to rely on the doctor's judgement to some extent. You don't want so much information you're confused and a decision is impossible, but you want as much information as you can reasonably be expected to take in. I wouldn't have the presumption to argue with consultants about their choice of an operation but I wanted to know that the risk was about 15% and that they felt that my son was a slightly better bet, and as they practise this new operation the chances are getting better all the time. I'm glad we knew that this is the best place. We were told the record in another unit is 25-30% mortality. It meant that if John died, which he nearly did, at least we would have known he had had the best chance.'

His wife added:

'When you go away and think about it and talk about it, that's when you think of questions to ask.'

A mother who had been a nurse said:

'I don't think you know the key questions at first. I think you start picking up little bits of information from each clinic and reading books and talking to other parents, you suddenly realise how things start falling into place, you begin to build up a pattern about your own child and then you can sort of start filling in the gaps or reinforce things when you go back to the clinic. You begin to understand what the doctor is saying. It does help if you can take home a diagram or something written about the defect to help you to sort out what they were saying.'

So parents relied on doctors to take a main share in deciding how much information to give and when.

A further means of limiting discussion may be intuition, that

doctors and parents sense agreement which makes discussion unnecessary. Joseph's mother had spoken of reluctance to be involved in major decisions about surgery. The question remains whether she would have responded differently if she had been more informed about the risks and benefits of surgery options. At the time there was a debate in the Lancet about withholding surgery from Down's children which was offered to other children. (Bull et al; Menahem; Wilson 1985) However the doctor seemed to be telling her what she wanted to know. In the words of another consultant on high risk surgery for Down's children:

'You can sense out the decision people have made and you make the decision for them you feel they want you to make.
[] When you start talking and they start fidgeting you can sense that they don't want surgery.'

Shanta 5 years Fifth clinic patient, 12.15-12.35am

Tetralogy of Fallot* and atrio-ventricular septal defect,* with other cardiac anomalies.

Shanta has defects similar to Joseph's but she does not have Down's syndrome. The consultant told the other doctors, 'We had a lot of discussion, [at the medical meeting] it will be very difficult surgery.' When the family arrived he told the parents that Shanta was growing too big for her shunt.

D: I think we should put her name down for a repeated catheter test... um ... to look very hard at er ... what we should do... The options are: easy - do the shunt on the other side, low risk, easy to do, of course that doesn't correct her heart. Or we have to think about, um, a bigger corrective operation, sort of open heart surgery, which is a big operation, um ... which would obviously have more associated risk... On the other hand I think we need to know exactly what her heart is like now, so that we can then discuss with the - what we think is her best bet.
[He continued talking about the need for more accurate information, implying although not specifying risk and at the same time reassuring the parents about Shanta's present condition.]

F: What does the open-heart consist of? What would you do?

D: Um ... she has a big hole in the middle with a common valve - with a hole above it and below it. So the surgeon puts two patches, one above and one below like that (demonstrates with a gesture) to block off the holes. We would then hope at that time that the, er, valve that was there works properly on both sides, because you've got a common valve and you make two out of them. Well perhaps we'd - and then the area that was narrowed would have to be opened up and probably a gusset put in to let it out - to

make it bigger so that the blood can go through to the lungs. So it's essentially - and then you take down the shunt she's already had. That's easy, you just tie it off. But it's - tricky, a big operation... We'd have to be certain it was the right thing to do.

[He explains that she may need another shunt instead of corrective surgery. The catheter was] to see if it looks technically er - to be reasonable.

[He starts teaching other doctors, indirectly warning the family that risk was very high in comparison with other cases, by saying]

This little girl is very complex, like the child we saw earlier but even more complex because [and he lists the complications. Eventually he turns back to the parents to say they would do a repeat catheter] and when we know the facts sit down with you and talk through what's the best thing to do.

M: Do you know when you'll do the catheter?

[After talking about the timing the family leave.]

Again, information is presented in order to persuade parents to agree, in this case to investigations, and to be open-minded about later decisions. Twice the explanations end in a short pause (-) as if the doctor began rapidly to explain medical concepts and then sensed a gap between what he was describing and the parents' level of medical understanding which seemed to him impossible to bridge so that he gave up the attempt and moved on to the next comment. It is easier to assimilate a group of new concepts, discuss and recall them when they are given in a chain of questions and answers instead of a single speech, when new ideas are built onto ones already understood, when they are clarified in a drawing, and when parents are invited to ask questions. That the parents did not reply to the medical account of surgery may partly be attributed to the omission of these practices.

The parents are advised to talk after the catheterisation. Specific risks are not mentioned. Risk remains a vague and also technical and abstract concept. It is alluded to in nonaffective, instrumental language, as a challenge to medical skill ('tricky', 'it's a big operation') and to medical reasoning, ('we'd have to be certain') but not a shared anxiety as suggested by the doctor who spoke of 'cold feet'.

Although families cannot make expert, technical decisions about surgery, when explaining decisions doctors can convey

either a sense of sharing some responsibility with families or of shouldering the whole decision and just informing them of it. Shanta's case is an example of formal encouragement to families to trust expert medical competence which, as discussed earlier, can have the effect of putting a barrier between rational professionals and anxious lay people. An informal approach attempts to overcome the barrier by admitting shared anxiety and thereby making parents more responsible in consciously agreeing to high risks. When what is being risked, the child's life or health and the possible effects on the family, is not mentioned, risk remains an abstraction. By definition 'risk' describes activity which is partly uncertain and uncontrollable, yet here it is defined mainly in terms of certainty, 'when we know the facts', and of firm responsible management and competence, 'easy' is said twice whereas 'tricky' hardly suggests serious perhaps fatal difficulty. The doctor hints at the limits of medical knowledge and ability to treat Shanta's problem, explicitly by stressing the complexity and need for more tests, and implicitly by phrases such as 'her best bet'. Yet the overall impression given is of confidence to meet the challenge. Medical uncertainty is presented in terms of precise expertise: 'we'll look very hard... to know exactly what her heart is like'.

Opinions and values are not explicitly referred to at this stage, although the medical advice rests on the opinion that it may be worth trying surgery which in Joseph's less technically complex case was not thought to be worthwhile. Shanta's parents are guided towards optimism in contrast to the pessimism about Joseph, so that the technical phrases actually hold profound ethical and emotional significance and influence. Asking parents about their opinion of the options could be regarded as an unnecessary use of time at this stage of uncertainty. Yet the approach so far has set a course likely to restrict the parents' contribution. They have been informed rather than consulted, and relevant considerations have been set within a discrete area of medical expertise and defined solely as medical technical criteria not, say, as including the daily quality of Shanta's life or the parents' feelings about taking high risks.

James 11 years. Seventh patient, 12.45-12.51am

Double outlet right ventricle,* ventricular septal defect,* pulmonary atresia.*

James had one shunt when a baby, 'a Waterston which we don't do anymore, so possibly there's [lung damage],' said the consultant, giving an example of how disadvantages of innovative treatment may not show up for some years, which limits doctors' knowledge and the information they can give to parents. James also had a Blalock shunt when he was nine. 'We had a lot of discussion about this child' at the medical meeting. The doctors talked of the difficulty of measuring pressures during the catheterisation. When James and his mother entered, she looked worn and worried and said:

M: Well I asked for this appointment um, we just want confirmation that ...

D: No change?

M: Yes[]

James: I think Mummy's just worrying about nothing really.

D: That's what mums are for. Very important that they worry, it's part of being a mum isn't it? So - James, you just slip off your shoes and go and sit over there [on the couch]. Do you think his colour is bad?

Mrs Bird gave a long answer, speaking very quietly, glancing at James as if vainly hoping that he wasn't listening to her fears and as if she would have said much more if he had not been there. She said he was now better after a long attack of 'flu. The doctors examined and discussed James then the consultant said:

D: He's okay, he could have many more years like this. To do a heart transplant on a boy of 11 would, I think, be irresponsible when he's reasonably well, but if in 10 years time he's blue and disabled and fully grown -. I think there are times when you don't rush in with um - er. I think you'll do for a year. [i.e. until next annual visit] If you're worried come back.

J: [Resigned] Yes, we'll be back.

[Everyone laughed. After they had gone, the consultant said]

D: 'We've had an hour talking with the family about all the surgical options. We think that there's such a risk that we'd better leave it as long as we can.' And he began his taped report, 'Mrs Bird was worried about James. He had a viral infection a couple of months ago. He's now back to his old self.'

One reason for using cases from a single clinic is to show the pressure to make a series of quick decisions. As a senior nurse said, 'We moan about some of the doctors' decisions, but we don't have to make them. I'm glad I don't carry that responsibility, I couldn't, but someone has to.' Some heart defects caused gradual lung damage. It was necessary to check that heart surgery was not left too late, to a stage when it would do the damaged lung arteries more harm than good. James was also one of many examples of the difficulty of deciding when the child's life was so restricted or deteriorating that he might be better off dead if not cured. This states the actual dilemma but not in words which a sensitive doctor would say to parents. Beyond the basic dilemmas of informed consent are further dilemmas about how clearly parents should be told, or expected to handle, the brutal truth.

How can doctors use their knowledge towards making decisions based on care, respect and justice? The scientific paradigm requires clear, objective rules. 'We've got to measure up the risks and weigh them up, the risks against the benefits,' said one consultant. When I asked whether you could measure and compare such qualities he answered, 'You've got to, somebody's got to make decisions.' So on the one hand doctors search for objective data, such as the pressures in the heart and lungs, which, when measured and assessed, reveal answers which can relieve part of the burden of making medical decisions by allowing them to seem less an arbitrary, individual response. On the other hand James' mother tries to explain her anxiety in the only terms which are acceptable in the clinic which are James's physical symptoms, his experience of being very tired and ill. However, she could not bring him until he had recovered from 'flu. His illness can only be described later in subjective ways; physical and mental feelings are the kind of nonspecific data which scientific assessment tries to avoid. A further problem is that she can only talk in terms of symptoms in which theoretically doctors are the experts; as she says she 'seeks confirmation', she cannot assert her case. Whether she wants confirmation that her fears are justified or not is left unclear because the consultant interposes 'no change'. I felt that she

wanted her worry confirmed that James' life was very restricted and they both needed extra support, not necessarily surgery. When he read this, the consultant disagreed. He said she knew that surgery would be necessary sometime and wanted to be told that it was not being left too late.

When parents seem likely to ask for treatment which he thinks is too risky, this doctor usually sets a brisk optimistic tone and remarks on the child's (comparative) wellness. Although he sympathises with the mother's anxiety, 'very important that they worry', he does not validate it; anxiety remains a nebulous response without a rational basis since James is pronounced 'okay' and anxiety is therefore dangerously liable to lead to 'irresponsible' decisions to 'rush in' unnecessarily. The medical discussion concentrates on safely technical abstract findings in which the experience of illness and anxiety are screened out.

Mortality is absolute but morbidity is relative and hard to define clearly. Different morbidity measures do not necessarily correlate, such as: actual physical lung damage; medical assessment of lung disease as partially examined, for example, through pressure readings; patients' responses to lung disease through their feeling of wellness or incapacity. Medical attempts to obtain objective records are complicated because morbidity is partly a subjective experience and people's differing reactions to disease interact with their physical state. Those who resist and struggle to remain active may have different physical reactions and prognoses from those who readily succumb and feel helpless and afraid.

How accurately do medical assessments of lung disease relate to the patient's present quality of life or therefore predict the future for this patient or, by analogy, for others? Which is the more salient measure or prediction, the patient's experience or the medical assessment? Cardiologists are devising increasingly sophisticated laboratory measures of haemodynamics and cardiac function on which to base clinical decisions. Yet some medical specialties are moving in the opposite direction, towards growing awareness of how the patient's subjective responses help to determine the course of diseases such as cancer. Greater

reliance on objective measures seems to be linked with less trust in the family's opinions. Children like James raise questions about whether more account should be taken of their daily life and personal views, whether dismissing anxiety helps them, and how they would weigh up risk and benefit of surgery if they felt that their lives were miserably restricted.

Sharon 2 years. Ninth patient, 1.03-1.09pm

Double outlet right ventricle,* ventricular septal defect,* pulmonary stenosis.*

Sharon has had one shunt and is thought to need a catheter test. Her paediatrician has asked that the test be done before September because Sharon's brother who has behaviour problems is due to start school and may be further disturbed if family life is disrupted then. Both parents enter with both children who are so noisy that the adults often leave sentences unfinished and words on the tape are often inaudible.

D: Do you think she's going bluer?

M: Yes.

D: Previous shunt is working nicely, going a little bit blue. What does she weigh now? [Looks at notes] 10 kilograms.

M: [to child who tries to touch an electric wire end sticking out of the wall] No, not there. [Child screams] Shut up.

D: We basically need to check she's in no danger. The shunt's still working well but we'll put her name down for the repeat catheter test to try to find out whether she's suitable for correction, or whether she'll need another shunt. My guess would be the former, namely that the shunt did its work very nicely and hopefully both pulmonary arteries have grown. It's obvious on the xray that the right side pulmonary artery is a good size and we need to check the left as well. Okay?

M: Yes. Oh, er my dentist - her teeth are going bad.

They talk about dental care being important for children with heart defects and where this will best be given, while the other doctors try to examine Sharon and discuss other patients. The parents' only question about surgery is to ask when the catheter will be done, and the consultant replies in three or four months. This will be around September but the parents do not comment. They shout at the children who grow noisier, screaming and

banging wooden bricks until they leave. The consultant tapes a report saying 'The parents understand the options.'

This example illustrates how consent is not a standard packet of facts which doctors can hand out in any context but that it is a reciprocal process dependent on the responses of the family and doctors to one another. The example also shows the constraints of the hospital systems on informed consent. After a long journey and long wait, small children who have missed their midday meal and rest become upset. Parents are expected to cope with the distress exacerbated by hospital systems at the same time as discussing complex problems but without the help of, say, a children's nurse or a box of well-chosen toys, just as they are expected to cope with problems resulting from admission dates which suit the hospital but not the family.

This is the first instance in the clinic of a formal request for parents' agreement to proposed treatment, ('Okay?' 'Yes.')

Doctors often reported their decisions and assumed agreement. Again there is the implicit question: what does being adequately informed consist in? Should levels of adequacy vary, and if so for what reasons? How much should the level depend on the parents' interest or competence in the consent process? Information has to be given in stages, allowing time for further medical investigation and for parents to learn. One mother explained how, through the fragmented process, it is hard even for persistent parents, after seven years of experience, to become well informed:

'When we were admitted again for a septectomy,* the houseman was extremely cagey about my enquiries and kept telling me to ask the consultant, but before I had a chance to, the surgeon's houseman called me to sign the consent form. There was lots I wanted to ask. He was quite good and gave me reasonable answers but kept repeating did I realise that this was very high risk surgery. I don't think I did realise how high it was. No one gave percentage survival rates or would tell me what happened to other children. I wondered even if there had been any other children having septectomies. He said the surgeon would talk to me, but we missed the surgeon's round.

I was appalled and amazed that they talked about high risk, dangers, etc. in front of Linda. She's very bright, so as well as being upset myself, I had to answer her queries about what "high risk" meant. I think it would be much better to discuss everything out of the child's hearing

and let the parent tell the child what they consider the child needs to know. Doctors should be available to offer advice on what the child should know, long before admission so she can be adequately prepared.'

Linda's mother then told me how her friend's son had had many problems with his two shunts before he died.

'So I was very scared and said to a consultant that shunts weren't always successful. He was snappy and just said the hospital had a very high success rate for shunts, so that shut me up! At an earlier clinic another consultant had said, 'We've discussed shunts before haven't we?' I said we had and we went on to something else, but in fact no one medical had explained to me what a shunt actually was. They seemed to assume we knew. I tried to explain to sister that I knew more about side effects of shunts (children having their voice box damaged or squints) than about the actual shunt. Eventually the explanation came at the foot of her bed after the operation.'

As in other examples, the child's presence, either through noisy distraction or anxious overhearing, prevented parents from talking freely. Linda's mother wanted medical knowledge to be given in specific forms that would help her and Linda to understand in personal terms, but to achieve this there had to be time to explain and translate information.

It may not be possible for parents to want to know medical details until their primary concerns are attended to. Sharon's family seemed to be too preoccupied with noncardiac matters to listen, in which case, informing parents can only be a ritual which achieves little beyond offering opportunities and fulfilling formal obligations.

Kelly 11 years Tenth patient, 1.10-1.34pm

Pulmonary atresia* and ventricular septal defect,* collaterals supplying the pulmonary arteries. Truncus type 1*

The doctors talked about Kelly waiting for a high risk operation which had been recommended by the medical meeting a year earlier. The consultant said, 'It seemed wrong to do it on a well child so I left it.' Kelly's surgeon would retire in a year and she could then be referred to a surgeon more experienced in the surgery she needed. They went into the next room to examine Kelly.

D: My impression is that she's slowing down a bit but she's still leading a fairly good life.

M: It does stop her doing things.

D: What things?

Kelly: Run - I get puffed when I walk uphill. [] I sometimes play games outside.

D: Not football? [Jokes about football.] The situation is this. There's a single great artery from the heart. The operation would close the hole and put an extra tube from the hole, plugging it into the artery. It's quite, um - I mean we've done lots of them - but the bigger the tube, the longer it lasts - maybe if we wait till she's adult size. The valve is a specially treated human valve but it's not quite the same as having your own valve. The operation - call it correction, isn't the same as having your own valve. It corrects the circulation but obviously it's not normal. It may be better to defer surgery, unless we're pushed into it for good clinical reasons, bearing in mind the quality of life and bearing in mind the risks. We sort of came to a conclusion in a rather muddled way last time to er ... If she has friends, and a good social life and it doesn't interfere with education - the question is should we get it over now?

[Kelly's mother looks worried.]

Understanding the desire to get it over and done with, but wanting to choose the optimal time... We're going to look at her data again, she's had two catheters, one last year, we'll look at it again - I will drop you a line indicating the sorts of risks involved but - we want to be sure we're doing it at the right time for the right reasons.

M: I wouldn't want to have it done unnecessarily, but she's becoming increasingly affected.

D: Yes, she's been remarkably well for a long time. Unless you think her limitations are too great, I don't see any harm in waiting.

M: She does get breathless, even getting out of bed.

D: She'll grow quite a lot in the next year or two, that's the advantage in waiting. []

M: [to Kelly] How do you think it's affecting you?...[Pause, but Kelly doesn't answer.] Don't know? She's too used to it.

D: Do you get breathless?

M: I think she gets perhaps frustrated sometimes. She stomps around.

D: Don't we all? [] All right miss, are you in a great rush for your operation?...[Kelly looks embarrassed]

M: She was very disappointed when it was cancelled last year.

D: Okay. [He leaves the room.]

Later I asked the senior registrar about Kelly.

SR: It's very difficult. I saw her last year, we all agreed we'd discuss her with the surgeons [] but then it was cancelled. Her mother said she is slowing down. [] It is maybe surgery with high risk, the pulmonary artery pressure is very high. [] I suppose they knew that at the

time, there's nothing in the notes about the risks. From our point of view you could lose the child on the [operating] table and her quality of life is good.

PA: What would you do if you were her consultant?

SR: I think I'd sit down and have a fair talk with her surgeon and refer her to the other surgeon if her mother knew the risk and agreed. I'd make sure they knew exactly. The girl is tense, psychologically the wait is not good. Last year she was completely asymptomatic and there was a lot of discussion. Now, from the psychological point of view it really would be better to do it now in the next six months. From a clinical point of view she has very high pressure in the lung arteries and she will not benefit from the wait. [] She will slow down, slowly. [] But I don't have all the political and emotional involvements with the unit. It's all very well for me as junior staff to say I'd talk frankly to the surgeons...[i.e. Asking a surgeon to refer his patient to another surgeon could disrupt staff relations.]

[Later the consultant said to the doctors, not the family] It is very major surgery. Last year it was very muddled, I think not unintentionally and in the child's interests. We'll discuss her at the next meeting.

The example of Kelly again shows medical redefinition of the family understanding of their experience in order to deter them from requesting risky surgery. Kelly's mother's pessimistic remarks tend to get an encouraging medical reply, 'she has been remarkably well'. Medical criteria such as 'good clinical reasons' take precedence over the family's criteria for assessing the need for surgery such as Kelly's frustration, (she stomps around), incapacity (she is breathless even getting out of bed) and anxiety. The doctor offers reassurance, 'she's still leading a fairly good life' and avoids explaining all the complications about treatment. Once more the child, lying undressed on the couch, becomes a barrier to communication as she seems to be unable to assert her views or to reinforce her mother's views firmly, and her silence is interpreted as assent.

Obviously there were many complicated technical arguments for and against surgery for Kelly and James. However, I gained the impression that the primary reason against surgery was the high risk of technical complications. If low risk surgery were available for children as limited as Kelly and James they would have it. Yet the secondary reasons against surgery tended to be stated, that the child was relatively well, with the result that secondary reasons tended to be presented to parents as if they

were the primary ones, the main basis for decisions. If this was the case, there were two consequences for informed consent.

First, parents' main concern was what they saw as their child's ill health. Yet their views came into conflict with the doctor's view if he wanted to confirm relatively good health. In medical terms 'relatively' could mean better than most children with this serious defect, or better than similar cases in which unsuccessful surgery had been attempted. Yet when the basis for assessing relative health was left unclear, parents were less able to state their views. So the consultant said to Kelly's mother 'unless you think her limitations are too great', and to James' mother 'if you are worried come back', but he seemed to leave them uncertain about what was 'too great', or what ought to cause worry. If parents were uncertain on what criteria to base their assessment of their child's health, it was difficult for them to know when to ask for medical help and how best to represent their child's interests in discussions about surgery.

The second consequence of emphasising the child's relative health was that the discussion tended to shift away from the families' main concerns. When formally told by an expert that their child was okay or would do, it was difficult for parents to continue to ask for help, perhaps other than surgery for Kelly's breathlessness and seeming anxiety. In another clinic, a father complained that his life was impossible as his wife cried whenever their son undressed because he was so thin. Knowing that patients rarely survived surgery for the child's defect, the consultant assured the parents that the boy was doing remarkably well and was merely skinny. If low weight could be acknowledged as a problem, perhaps a dietician could have offered practical help. In the tertiary system, paramedical help was supposed to be arranged by local paediatricians and GPs. Yet problems were not always referred back to them. Sometimes doctors seemed to try to protect families from full knowledge by mediating parents' understanding of their child's condition, redefining anxiety, changing 'very thin' to 'skinny'.

Informed consent is an ideal which cannot be perfectly realised and, as law cases show, no one is agreed on the level at which obligations are reasonably fulfilled, how many topics should be

raised, how fully each should be explored, or what it is 'absolutely necessary' to know. Doctors and parents are constrained by limited time, by the customs of normal conversation and the difficulty of ensuring whether topics discussed are either understood or accepted. The adults have conflicting obligations to the child, yet also to the efficient and fair use of hospital time and resources. Parents' freedom to consent can perhaps best be demonstrated by freedom to dissent to medical advice, even on minor levels of asking critical questions about decisions. This freedom is restricted when the expert doctor defines topics such as quality and length of life solely in medical terms of cardiac function and haemodynamics. Subjects in which families are knowledgeable, the child's experience of illness, their value judgements about risk and benefit of surgery, tend to be closed off from discussion. There are underlying questions about what constitutes valid knowledge. Clinical discussion included implicit social value judgements, for instance in assessing risk and benefit of surgery for Kelly, or the differing advice given about similar surgery for Joseph and Shanta. It was difficult for everyone to talk openly about risk and harm, anxiety and possible failure, especially with children present; the doctor seemed to feel a duty usually to encourage confidence and optimism.

My description of the clinics has omitted the crucial ingredient of the ways in which people related and intuitively became aware of feelings. The doctor quoted as saying that when parents started to fidget he knew they did not want surgery, alluded to this interaction. Yet there seems to be no method in sociology of conveying what Halmos (1965:192f) called a 'vitalist' understanding of, say, kindness, sympathy or reverence. The problem of trying to convey these qualities is that they can only be observed and recorded subjectively and 'unscientifically'. (p118) There is a risk of 'mushy thinking' and sentimental accounts. Yet as Halmos says, to assume the opposite extreme is to fall into the trap of 'mechano analysis', imagining that only that which can be explicitly demonstrated and atomised is relevant, or else attempting 'to disperse our mystification by fragmenting the opaque totality of an

experience'.(p98) Halmos thinks that reverential language is needed to convey opaque and total experiences of rapport or trust (p59f), a language balancing objectivity and subjectivity, logic and sympathy.(p119) In trying to avoid mushy thinking, I may have given too harsh an impression of the clinic, implying that impersonal medical discussion expressed deliberately impersonal indifference. This would obscure doctors' intentions to benefit which were shown through their healing work as well as in looks and tones of sympathy, which are difficult to identify and record.

It is difficult to describe in this thesis qualities of compassion and respect which are needed for understanding informed proxy consent. It is perhaps far more difficult for doctors to discuss them explicitly during medical case conferences, dedicated to basing decisions about surgery on objective, technical decisions. The next chapter considers the way doctors deal with objective and subjective knowledge when making decisions about surgery. This was the next stage in the consent process following the outpatient clinic and, in some cases, admission for further tests such as catheterisation.

CHAPTER SIX

THE MEDICAL BACKGROUND TO INFORMED CONSENT

Scientific medicine has let into clinical medicine a new spirit of criticism and questioning. [] The danger is, however, that [] a new authoritarianism will replace the old one. For the greater the expectations we place on the doctor the more may we strengthen his need to maintain his role, and while attempting to satisfy others, to satisfy himself. [] There is a danger of medicine becoming a technology. [] The task of the future is to make medicine more 'social' in its application without losing in the process the benefits of science and specialised knowledge.

(R Titmus. Essays on the welfare state, 1958:200-2)

Children's heart surgery clearly illuminates problems of informed consent because, (unlike routine minor surgery or much GP medicine), it is usually discussed in a clear series of observable stages. Having collected data, the cardiac teams would usually discuss the pros and cons of surgery in a formal meeting before making final recommendations to parents. This chapter considers how decisions about surgery are agreed at medical meetings as a background to discussions with parents. It compares the kinds of information about surgery which doctors, and later parents, select as centrally important, and sees how the meetings influence the consent process. A main theme of this chapter is explained in the words of a surgeon at the children's hospital:

'The management of the child combines technical and social aspects. At times these aspects have to be combined like two pathways meeting. But at some stage, each has to be considered separately. At the JCC (1), you must have complete objectivity, and then go on to the final discussion with the parents. Deciding how much of the social to take into account when making medical decisions - well that is a very important issue which needs deep thought. I think we do talk about that a lot in the JCC.' (1)

Medical team work

Gynaecologists work both as surgeons and physicians; their patients are normally treated by one consultant. Cardiologists

1. JCC -Joint cardiac conference refers to meetings at CH.

and cardiac surgeons divide the medical and surgical work between them, although in overlapping ways. They are concerned with risky, varied, unusual and complex cases, and with a vast body of knowledge continually increasing and needing to be assessed. Some of the work attempts to enlarge the boundaries of medical expertise and requires team decisions about how cautious or radical the attempts should be. All these characteristics encourage teamwork. As one doctor said:

'It is difficult if you make decisions and the child dies. It's easier if it's made by a group of us at the meeting.'

The meetings had several purposes: to decide if surgery were advisable and if so when and of what kind; to 'collect specimens' by reviewing data of unusual cases or cases which seemed to be part of a trend to be identified and counted; to learn and teach about the defects, treatments and how to present cases, analyse data and make decisions; to record every diagnosis for computer records used for reviews and research. The meetings ensured that each case was considered carefully, usually at least twice, after catheterisation and before surgery; they were also concerned with the general advance of medical knowledge, and helped to reaffirm the purpose and value of the work in each unit.

In the children's hospital patients were 'JCCed' at conferences held around midday three times a week. A junior doctor presented the patients' history, xrays, echoes and data taken during catheterisation. The angiogram* was reviewed. After treatment had been discussed a consultant cardiologist and surgeon wrote the decision on the child's JCC form, both signed the form and the cardiologist undertook to write to inform the parents. 'The form records the nubbins of the information so that everyone knows what has been agreed', said one surgeon.

Between three and twelve doctors attended, sitting around a large table. Most of them spoke and the three senior registrars in surgery were often asked for their opinion. Surgeons seemed to take the major share of making final decisions. The meetings were friendly and leisurely, pausing while surgeons were called to theatre. Sometimes food was served. Often there were long silences while everyone thought about a problem. These were

difficult meetings to observe because the doctors worked so closely together that they did not need to explain everything fully. They would imply an answer with a glance or a nod, or murmur quietly together. Many doctors said they valued the close, friendly teamwork. When I asked if families did not feel confused because they were so much shared around a large team a doctor replied, 'Oh no, because we all get on so well together here.' A surgeon said:

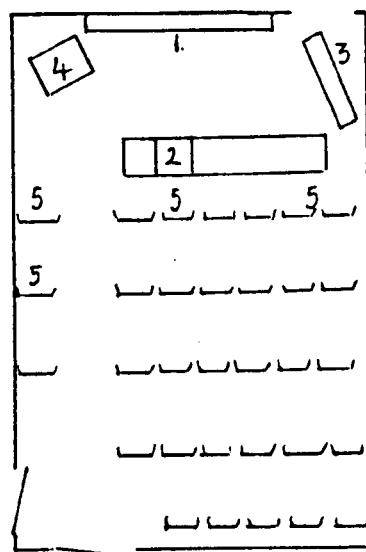
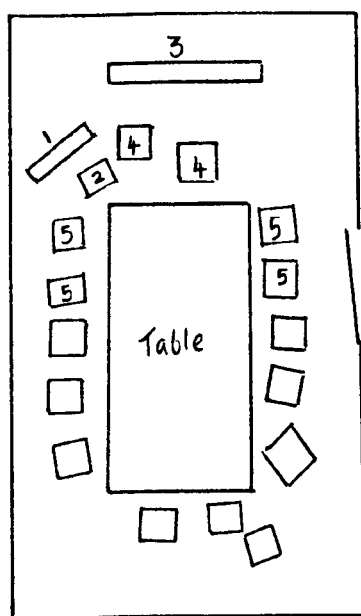
'We never reach a decision on our own. It's almost unheard of for us to make a spontaneous decision of radical

Figure 2. Plan of the conference rooms

The room settings were associated with the contrasting work contexts of the meetings.

Children's hospital

Heart hospital



Key 1. Screen for angiograms 2. Angiogram projector
 3. Xray viewing screen 4. Video TV for echoes
 5. Consultants. About four attended meetings in each unit.
 Different consultants attended on different days at the children's hospital. The heart hospital meetings included one or more consultants who treated adult patients.



— / Chairs for junior and visiting doctors

treatment. In each case surgery is discussed at least three times in a major way, once by the cardiologist, twice at the JCC. It's pretty unusual for a wrong decision to slip through. [] In my experience the JCC is unique. It's what made me stay here. I felt that the decisions which were being reached about the patients were being made on as logical, as informed and as caring a basis as possible in the British system.'

In the heart hospital everyone sat facing the data and discussion tended to be rather intense, critical and rigorous. Meetings were held on Mondays from 8.00am for two hours or more. All the data were reviewed except echoes. The meetings were formal, concentrated and uninterrupted. Twenty or more people attended, including nurses, and doctors from other departments and from abroad, with senior doctors at the front discussing cases and everyone else mainly listening. Usually only the one surgeon who operated on most of the children attended intermittently with his team of three junior doctors. He took less part in discussion than the JCC surgeons. This was a formal occasion for teaching and learning. Junior doctors presented cases in a concise formula, and consultants summarised the main questions and teaching points.

Recording decisions

At CH, the eight consultants' secretaries regularly checked through the waiting lists, labelled children's files and stored them in sections for pre-catheter and pre-operation. At HH the three secretaries, one partly dealing with adult patients, did not have time to keep lists, and in order that waiting patients should not be forgotten, much depended on files, letters and messages not being mislaid. After HH meetings, the registrar who presented the cases had to write up decisions and arrange the next stage, such as a letter to the surgeon asking for the child to be put on his list. The registrar would have been on duty since Friday evening, and would be working through until about 1pm on Monday presenting cases on the big ward round. I wondered how they could remember the essential details of each complicated discussion and when they would get time to do the paper work. They told me that it was often difficult to find the time and to

be sure of, and to remember, the essential details and final decisions. 'It's a system full of loop holes,' said one doctor, 'and it's amazing more cases don't get lost. They rarely do and I think that is because people work incredibly hard and carefully.' One safeguard was that children tended to be seen consistently in clinics by the same consultant, which helped to ensure that they were regularly reviewed. At CH, perhaps because team work was so important, children did not have this continuity of care and careful records were therefore more vital.

In both hospitals, especially in HH, the staff were working within extremely difficult conditions. Their concern that there was never enough time increased the stress of their work. Doctors have to concentrate intently on each case, yet at the same time be ready to switch attention instantly to other cases, in the busy wards or when the phone rings. Despite the tensions and interruptions the staff were almost always very polite, helpful, and willing to give time to answer questions to anyone.

Informing and involving families

The organisation in each hospital had advantages and disadvantages for families. It seemed that, at CH, because the JCC and the surgeons' opinions were so important, outpatient clinics were primarily for collecting technical evidence for the JCC, and less for making decisions and discussing these with families. Xrays and ECGs were often taken after the child had seen the consultant. Families were warned in the clinic what would be the likely decision but often it was qualified with, 'when I have talked with my colleagues, we'll let you know what we decide.' A carefully worded letter, sometimes including the percentage mortality risk of planned surgery, was sent after the JCC so that parents had definite written news from a named consultant they could contact if there was uncertainty or delay. Yet this system was in some ways impersonal. A letter was necessary if families were not told definite conclusions in the clinic, and some families might feel that it was easier to negotiate during a clinic discussion than to question a formal, recorded committee statement.

A cardiologist at HH thought that xrays and ECGs were

'essential' preparation for most consultations. With them, he often knew the diagnosis before seeing the child and felt he could use examining and discussion time with the families more efficiently. He thought that each case should be managed primarily by the child's own consultant, not by a committee.

One mother, a nurse, explained pros and cons of the CH routine, the differences between continuous care from a known doctor and shared care among a team, the importance to her of doctors knowing the child and family, and of moderate, 'questioning' medical practice.

'Dr R said, "We all get together and discuss these cases and then we'll let you know." And I thought how super, it was uplifting. We were filled with such confidence in their ability to do the right thing and make the best decisions. It was amazing when Robert was first admitted, several high-powered looking doctors descended on him and told us all they were doing. I felt a sense of privilege really. We were overawed.

But the doctors don't all see it from the parents' point of view. I'd prefer to have a clear decision at the consultation but if you don't see your consultant you get a sensation that the other doctors can't make decisions. Continuity is terribly important. Doctors must do their homework. I told one doctor that my child had had a valve taken out and he said, "Oh no, he never had that done." I felt terribly upset because I knew I was right. We saw different doctors in the clinics and they told us conflicting decisions. We wrote to Dr R and he wrote a nice letter back saying it was a mistake. But lots of people don't know they can write. It's such an advantage being white and middle class and articulate. It's not what you know, it's who you know.'

'And how you are known', the mother might have added; how much doctors understand the family's view. She continued to talk about the relation between the doctor and the family.

'Now we always manage to see Dr R. He's confident in an intelligent, questioning sort of way, he's honest. You're treated as if you are part of the process, not just a number. He sees the child as a member of the family; it horrifies me that there are people who don't function like that. I think sometimes Dr R is aware when that is going on but there is not much he can do about it.'

Centering decision making into the JCC shifted it away from the family. Their views could only be represented very briefly and impersonally, if at all, by the doctor who had met them and who

might feel that he could not 'do much about' conveying awareness of the whole family. In outpatient clinics, anxiety or relief were conveyed vividly although not always in words. The atmosphere of the medical meetings, concentrating on technical knowledge, was not conducive to discussing personal details, or the vitalist awareness which Halmos (1965) identified, however important the doctor who knew the family might consider these to be in the clinical decisions. There was the question whether the basis for wise surgery decisions rested on scientific detachment or on involvement with the family. There is a danger that mechanical notions of what is technically feasible will obscure the costs to the family, and that 'risk' will be defined as prediction of probable achievement instead of assessment of possible harm to the child. Halmos would perhaps argue that a 'creative dissonance' is necessary, tolerating and using paradox such as of subjective objectivity, involved detachment (p175). This suggests that decisions need to be informed by the experience of being with the family, not just by a report of them. Doctors seemed uncertain how to combine detachment and involvement, informing parents and asking for their opinions. A cardiologist told me, 'We write to parents to tell them of the JCC decision and invite them to discuss it at the next outpatients'. Yet a surgeon told me, 'More or less, parents accept our decision by our team at the JCC'. However at one meeting he said:

Surgeon: Palliation has a better survival rate than repairs, but long term ... It is very, very ...

Reg: I saw one very, very well child on Tuesday, palliated.

Surgeon: Yes, yes..., if -. I'd be slightly more inclined ... if it was my child.... Talk to the parents. We have a 90% mortality, look...um.

Cardiologist: She won't survive. She's very breathless.

Surgeon: It's not urgent. Leave the parents time to talk.

Sen. reg: They're very dependent on what we say. They'll follow what we tell them.

A registrar came in to say a child had just died in the theatre and went on to talk about another patient they were concerned

- short pause; long pause; [] words omitted.

might not survive much longer. This illustrates the pressures on surgeons to keep some distance from families when they are so directly involved in fatalities. Another surgeon whom parents found very kind and supportive, talked to me about the authority of the JCC and the extent of parents' freedom to respond to JCC decisions, also about the difficulty of making technical decisions when feeling personally involved.

Surgeon: Because of the very technical nature of the job, and the fact that most of the decisions we have to make are very tough in terms of life and death, - quality of life, the social side of it does tend to get pushed into the background. [] The emotional side of it does tend to get displaced, and I think it has to, to produce clarity of decision about the haemodynamics to some extent. Because you've got to concentrate completely on these problems for short periods of time, to get the decision right. Some are very unpalatable, with a high risk. Nobody wants to go back and operate on Nicholas again, but we've got to. It's his only chance of survival.

That doesn't mean to say that is "the decision". That means that is what we have advised as a team. We then go and discuss it with the parents. So we need a venue for that kind of clear policy. But we don't carry it forward without a potential for modifying it with the views of the parents. And if his parents said, "We've had enough, no more," I don't think any of us would think they'd made an unwise decision. Personally I would say to them, "If it was my child I would have another go. Let's try once more."

PA: Do you think that might put intolerable pressure on parents? They might feel they could not refuse?

Surgeon: No, no. I think by that stage they know full well what they are doing. It's not intolerable, it's a position of great relief.

PA: But what if you do sense, maybe it's gone too far?

Surgeon: Some doctors are more open to that suggestion than others, and some find it easier to do than others. It would be naive of me to say that every doctor was capable of handling that kind of situation. I don't think it can be easily taught. It's part of the personality, so if the decisions that we reach, have to be made away from that kind of -. The clinical decisions, I think, must be made coldly. Not coldly - that is without any emotion -. They must be made on the basis of medical evidence. What is correct given the data that you have available. If there's more data, or the parents say "No," or you feel you want to influence the parents in another way, then I think the decision you have reached is wrong. You've got a whole new problem. And then you adapt that decision on the basis of other factors, you take it back to the JCC.

PA: Do you find that you have to select what you consider to be the main arguments, you've put them in a certain balance, so inevitably you're slanting your

information?

Surgeon: I'm not frightened of slanting my information one way or the other because we've already made a decision in the JCC what's best for the child.

The surgeon raises the questions of what are the appropriate data for the JCC, how much should social information be combined with technical issues, how personal or impersonal should the doctors' approach to cases be? Also, how much are parents objectively informed or subjectively influenced?

The Nuremberg Code advises that patients giving consent (for research):

'should be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion.'

Earlier I wrote that this concept of free choice could be applied to consent for treatment if patients, though feeling coerced by the nature of the illness, did not feel coerced by the opinions of hospital staff. However, parents' main knowledge of the child's condition is the medical diagnosis and prognosis, which cannot be wholly objective and impartial, especially in complex, high risk cases. There is rarely a clear, single truth and knowledge and hope cannot be totally separated. The surgeon continued to talk about finding a balance between detachment and involvement.

Surgeon: There are ethical questions, value judgements that I feel I must not make, unless pushed into a corner to make them. I help parents. I help their beliefs and opinions. But I'm here to do a job, to make that child better in the best context for the family. I'm not always in a position to have all the data which enables me to make that decision. I've got to sense it.

He seemed to consider that it was more ethical to offer surgery than to withhold it, and went on to say how if he needed to persuade parents to accept that no surgery could help a fatally ill child, 'which I realise is contentious in every possible way' he would keep talking about risks and problems until:

'eventually they'll say to you, "Is it worth going on?" and that's when you start debating with the parents themselves,

and some consensus will emerge.'

Doctors needed to emphasise detachment in medical decisions partly in self-protection. When their decisions could be regarded as determined by scientific rules, the burden of personal choice and involvement was less apparent. Families reintroduced personal significance into both the content of decisions and the manner in which they were presented and discussed. The surgeon talks of relating to families as 'part of the personality' and then immediately says that a more detached approach is necessary in making decisions.

Themes in the medical meetings

Issues which became clear through observations of medical meetings were: the pressure on doctors, as in the clinics, to make rapid decisions; the difficulty of separating medical and psycho-social considerations; different measures of morbidity - clinical or through the patients' experience of wellness or incapacity; the difficulty of predicting the precise nature of some surgery until the surgeon could assess problems during the operation; problems of allocating limited resources.

There were two dominant themes through the meetings, chronic illness and risk versus benefit. To quote an average HH meeting of 14 cases: three seemed likely to recover well; in two cases there was some doubt about the type of surgery to offer; in eight cases children had experienced months or years of chronic illness which could be alleviated but not cured, (a baby of seven months had always lived in hospital and another baby died shortly after the meeting); one fatal condition, hypoplastic left heart, could not be treated. Meetings represented the workload of the unit, but not the success rate, because cured cases were seldom reviewed whereas sick children were repeatedly reviewed.

Chronic illness led on to the other main theme, risk. Doctors balanced high mortality and morbidity risks of surgery against risks of postponing surgery until it was too late, and against harms of chronic illness and severe incapacity. This is the connecting point between medical knowledge of technical risk and social knowledge of the experience and values of the family.

Social knowledge possibly had slightly more influence on

treatment decisions at HH, I suggest for the following reasons. Harmony in the JCC at CH seemed to be associated with acceptance of surgeons' decisions which were likely to be biased towards surgical treatment. Argument in HH meetings concerned a tension between technical and other matters, between the surgeons' wish to decide on the best operation and the cardiologists' wish to review all the options including medical (i.e. non-surgical) treatment. In closer contact with families, cardiologists were perhaps more aware of what risk would mean to them and, as the surgeon said earlier, could 'sense' the data indirectly through being with families as well as directly by talking with them. Secondly, because the decision was not formally recorded and signed as at the JCC, HH cardiologists could discuss and revise decisions with families with more flexibility.

My interpretations of policies are based on interviews and on observations of meetings. It would be difficult to demonstrate adequately that one unit was more cautious about surgery than another without a medical comparison of carefully matched cases and a study of how meeting decisions were carried out. Even then, information would be missing, because hospital policies select out cases before they arrive, such as the Down's children who are not referred to units when the known policy is not to operate. The paper by Bull et al (1985) is an example of a conservative attitude towards surgery at HH but also of a low surgery rate for this defect at CH, compared with American units.

Suggesting that the HH system enabled cardiologists to provide the more personal, family centred service may seem in contradiction to the previous chapter when the children's hospital clinics looked the most attentive to the family. The hospitals were both full of contradictions in relation to achieving informed consent, because members of staff held differing aims, and because many activities resulted in both advantages and disadvantages for patients. The form and content of children's clinics were influenced by doctors interested in paediatric care, yet they were working within larger systems which were also influenced by other doctors.

Examples of parents' and doctors' views of informed consent and how these may be influenced by the medical meetings

The case of each child can present dilemmas of knowledge and of responsibility. The dilemmas concern opposing emphases, such as: scientific versus subjective knowledge of the child; medical authority versus parents' responsibility; quality of life as a clinical assessment or as a daily experience; and so on. The medical meetings illustrate the pressure on doctors to treat these differences of emphasis as alternatives, to separate the pairs and to exclude nonmedical considerations. In contrast, parents attempt to unite these different values, to share responsibility, to combine different types of knowledge and to connect medical treatment with the child's daily experience.

Since there is no general solution, for example, as to when surgical risk is too high, a decision must be made in each case. Medical decisions would demand far too much time and emotional involvement if doctors did not select reasonably objective and manageable criteria for continually making difficult decisions throughout their career. Connecting medical and social values is therefore a problem for doctors, yet separating them can be a problem for parents.

The ways in which doctors and parents tend to work in opposite directions is central to their interpretation of informed consent. Consent may be seen either as acceptance of a medical proposal, or else as working towards agreement within medical and social contradictions, in which compromise rather than complete reconciliation may be possible. If parents dissent, in the first view of consent, doctors are liable to offer more explanation and reassurance. In the second view, doctors may consider parents' reservations with them, and possibly modify the medical decision. Examples in which parents dissent from doctors' recommendations can clearly illustrate the parents' influence in the process of working towards agreement. Two examples will now be given.

Life or health

During my interviews, mothers tended to express more reservations about surgery than fathers did. The main reservations are all given in this example of Tom Ayres, who attended a third hospital

linked to both the hospitals observed. First there is concern that surgery is not in the child's best interests. Mrs Ayres said of her grossly brain damaged three year old son:

'Their whole thing at the hospital is to help save life. I think he's got no life whatsoever, and he should be dead. But my husband is saying, "Do everything that you can". But it's not going to help Tom.'

Tom's case illustrates the conflict in the centuries old debate summarised in Dunstan and Seller (1983) between saving life at any price, an ethic they associated with Jewish paternalism, and choosing a minimal quality of life, without which death may be preferred, an ethic associated with Greek and Christian traditions and Kantian concepts of personal autonomy. Each tradition perceives the patient's interests in a different way, ultimately as existence or as tolerable life. Mrs Ayres said:

'We both passionately believe in what we're doing. My husband loves his children so completely. He thinks we must let Tom go on and on and on, - as a cabbage. I think he's had enough as well as us. He's skin and bone. Sometimes his eyes look as if they're saying, "Oh, for God's sake, Mum!" Who wants him to live with a brand new corrected heart?

I would like to talk to someone neutral, but there is no one. Our paediatrician said, "I'll back you in all you decide, but you've got to decide with your husband, there's nothing I can do till then." It's affecting our whole family life, even the grannies are split over it. I don't feel we'll ever come together, there is no sensible compromise.'

Some parents are concerned that medical advice may be guided, not by concern for the particular child, but by doctors' strong adherence to the ethic of survival. Technological advance has complicated *practical* choices in many cases by enabling prolonged existence without health. Through this very machinery with the enormous effort and cost directed towards prolonging life and defeating death, modern medicine has also perhaps complicated *moral* principles and choices. Technology has raised conflicting expectations that we should not only live much longer but also enjoy far higher standards of health than until recently was thought possible. Victorian moral standards of cleanliness have been replaced by strong connections between morality and health;

'look after yourself', it is our duty to be healthy and to ensure the health of our children. Yet we do not know how to reconcile the values of health and of life when they conflict.

This technological complication connects with parents' second reservation about surgery. There is concern that doctors are biased towards intervening because, even if surgery will not benefit the child, the knowledge gained may benefit other patients. Mrs Ayres feels 'held to ransom' by such medical pressures, an image of being totally restricted until the price can be paid and the key found to release her from her dilemma.

'I feel we're being held to ransom at the hospital. It's not to benefit Tom, but for research. That's no good, no benefits, except to others. I don't want him to be a guinea-pig.'

A third reservation is that hospital staff are orientated towards saving life in routine defensive medicine. The ethic of saving life is easier to define with the unanimous agreement and action of all the staff and the family, than is the ethic of health, of agreeing on what constitutes a minimally tolerable life and what should be done if a patient seems to be existing below this level. Because the principle of minimal health is far more uncertain, contentious and tied to personal beliefs it can disrupt hospital routines designed for efficient mass care and for preventing litigation. Mrs Ayres said:

'I think it is a problem for the hospital. He had a red sticker on his file, "Don't resuscitate," but they did.'

A further concern was Mrs Ayres' sense of helplessness that she could not influence decisions, because the consent form is vaguely worded and assumes that parents share a unanimous decision.

'Can they operate without one parent's consent, and who counts most? I'd hate to think my husband can sign the consent and in the background I'll be screaming, "Don't do it". There's such a vagueness on the consent form about "any other necessary doings".'

The fifth reservation against surgery was that caring for the child who barely survived would be an impossible strain. This

usually affected mothers' lives far more than fathers'. Mothers were concerned about how all the family would be affected, not only by the drain on their own energy but also by the strain of daily living with the sick child, with the continual practical impact of realising and grieving over the child's restrictions.

Tom was on 22 drugs. It took me hours to get them down. He'd bring some up and I'd wonder what he'd kept down. So I have decided to stop stuffing all that garbage down him. It makes me mad when people say I'm lucky not to have to explain to Tom.[] He is at home all the time. I never get a break. [] Emotionally and mentally I find it far worse.'

Through living so closely with the child and sharing what she sees as his futile suffering, Mrs Ayres is likely to favour parents' freedom of choice. She considers that for Tom and the family his death may be preferable to his existence. Doctors work to a rapid time scale, seeing the child fairly briefly and making quick decisions; the parents' time scale can move very slowly, small details acquire enormous significance, and these differences can create very different perspectives of the child's case.

Withholding consent

The following untypical example, from CH, is used because the parents wanted to have an unusually clear part in the medical decisions. The example shows attempts to choose between the ethic of saving life or of tolerable health. It suggests the limits to which doctors working in the JCC system thought that parents could influence decisions. Parents' dissent can help to show where the line is drawn between medical paternalism, (doctors' wish to take what they believe to be the best course for the patient), and respect for proxy patients' freedom of choice. Tensions in the classical dichotomy in medical ethics between paternalism and respect for patients' autonomy are especially complicated in cases of child patients. Paternalism can be regarded as an appropriate response to the child, and respect for the patient often means respect for the views of other adults, the parents who are acting in a paternal role.

There was medical uncertainty about the harm and benefit both of mitral valve replacement and of refraining from surgery.

Either course might cause, continue or prevent the ill health which everyone wanted to avoid. Surgery could be regarded as a harmful or as a helpful intervention. The purpose here is not to examine these philosophical and medical questions, but to see how decisions are shared between doctors and parents.

David Hughes was two weeks old and looked breathless and agitated. His parents were standing by his cot tube-feeding him. They thought that he became more breathless when he had a large feed every four hours, but he had to have this to fit the nursing rotas. The Hughes had opted to stay with friends because they felt that was the best way they could cope. Mr Hughes told me that the cardiologist had said to them that David

'has an ASD* and a mitral valve* problem. His valve might need replacing but he said he would not choose this for any child of his. We feel that we are in a dilemma. David is breathing very fast but if this clears up he may not need surgery. We don't know if his diarrhoea is making him worse and more breathless.'

Two registrars arrived. Mrs Hughes said she was worried because while she was away, David had mistakenly been given SMA milk instead of her own expressed breastmilk. The doctors said that this had probably caused David's diarrhoea. David's parents became more upset. The registrar said,

'Fluid loss from the diarrhoea isn't a problem. Without it she [sic] would have to be on diuretics* and SMA is doing the trick instead'.

While the parents' attention centered on David's whole state of health and how this connected with his nursing care, the doctors separated everything from the cardiac condition except in how it indirectly affected his fluid balance, an important factor in heart conditions. Mr Hughes said he would come in from Islington to give the 2am feed. The doctors did not reply to the parents' concern about the quality of nursing care and how this might increase the need for surgery.

Registrar: I'm almost 100% convinced the problem is not the valve itself but growth of tissue above it. That could be cut away with little risk and no need to repeat the surgery. [] We see more of these cases than anywhere else. I've reviewed all the literature and looked at all our videos on this condition.

Father: Dr X (consultant) said ten years ago all children with this died. I think he said something about a lot of children with mitral valve replacements die, or at least they've never done one on anyone so young. And biennial valve replacements will be necessary.

Reg: No, it's nothing like what you think. It doesn't mean ops every six months, of course we wouldn't consider anything like that. It means a replacement after two or three years, then another later but perhaps not more than three operations. But of course, we can't tell now, it depends how fast she grows. We put in the biggest valve possible [and he continued with technical details.] We can't be certain until the surgeon looks at the open heart. Doctors only decide to do what is sensible and in the child's best interests. They wouldn't consider anything that was too much for the child. You just concentrate on the baby and leave the decisions to us, we know the best thing to decide.

Concentrating on technical details enabled the registrar to emphasise his medical knowledge, thereby implying his wisdom to determine the child's interests. It also enabled him to shift the argument from *whether* surgery might be done to *how* it might be done. The parents did not mention that the child was a 'he', or say that 'biennial' means every second, not every half, year and therefore was not so different from the registrar's prediction of the near future. They said they wanted David's condition to be treated unless he needed a valve replacement, in which case they wanted the surgeon to stop, in mid-operation if necessary, and close the heart without carrying out any treatment. The registrar looked amazed.

'But you can't do that. You have to leave the decision to the surgeon. [] And anyway the decision is made by all of us in committee, all the experts together, we decide what's best, up there. [i.e. upstairs in the conference room.]

Although the consultants tended to speak in a less direct manner, and may have wanted to avoid making parents feel clearly coerced by a powerful committee, the authority of the JCC could be presented as a formidable power by junior doctors. When the registrars had gone, the parents looked red-faced and angry and argued together, his father wanting to pick up David, his mother saying this made him more upset. Mrs Hughes told me that she had had heart surgery as a baby with a 70% mortality risk, and had spent much of her childhood in a wheelchair.

Mother: When I was five, I only attended four half days at school all my first term.

PA: So you want to save David from that sort of life?

Mother: Oh no, it wasn't for me, it was for my mother. I was only five so I wasn't aware of what was happening. I just don't want that sort of life. I want to go back to work. How can I if he's ill like that?

Father: [Turning away angrily] Oh, I'm having nothing to do with that sort of talk.

David's mother foresees, or remembers from her own childhood, the family pressures of chronic illness, which Tom's mother is experiencing, and she doubts whether she can or should cope with them. (I did not like to ask Mr Hughes whether he would give up his career if necessary.) When parents feel that breathlessness, diarrhoea and agitation cause the child to suffer, their evaluation of what makes life tolerable is likely to be influenced by contributory contingent factors which may be discounted in theoretical judgements. When parents judge on subjective levels, it is difficult to distinguish between their own and their child's interests, and where these converge or conflict. Yet since the child is so dependent on the parents, there is the question of how far doctors can help children by strongly recommending treatment and by trying to prolong life against the parents' wishes.

David's parents were anxious that the consent form was vague. The CH form states:

I hereby consent to the submission of the above child to investigation by..... and operative treatment for the purpose and nature of which have been explained to me by Dr/Mr....

I also consent to such further treatment or alternative measures as may be found necessary to the investigation or during the course of operation afterwards, together with the administration of general, local or other anaesthetic for any of these purposes.

The HH form was similar except that 'effect' was added and the same form was used for adult and child patients implying that the adult signing the form was the patient. (This has since been changed.) The form began:

I hereby consent to undergo the operation of ... the nature, purpose and effect of which have been explained to me by Dr/Mr

Both forms are partly designed to provide essential protection for doctors against potential litigation and to leave some freedom of decision open to surgeons.

A week later, when I asked David's consultant for his views, he immediately found a room to talk, sat down and gave his full attention for about half an hour. I thought he was a very conscientious and well-intentioned doctor. His reply is given at some length in order to illustrate characteristics which he shared with many of his colleagues and which were demonstrated both in what he said and in how he handled my questions. These were: to concentrate on the topics which he selected; to want, as he said, 'to help' by giving positive and definitive answers; therefore to tend to avoid what he called 'difficult, straight' questions on matters where he felt doubtful; to perceive questions about choice as enormously complicated by medical details, in which moral issues tended to be submerged in technical examples; to emphasise medical authority and knowledge, but to share with the registrar uncertainty as to who holds final authority, the medical team or the individual surgeon; to be frank about medical limitations but in a general abstract way unrelated to particular patients.

PA: And they were saying if it was a question of replacing the valve they wanted the surgeon to stop and close the heart and I wondered if you thought that parents can ask surgeons to do that?

Cons: Not really. Essentially, I mean,

and he began a long account of David's condition and the nature of valve problems. He spoke slowly and clearly, with much repetition, emphasis, and in the manner noted with other doctors of describing uncertainty with definitive precision. For example:

Cons: One of the areas one looks at is the left sided valve, the mitral valve, and in David's case his mitral valve or the area of his mitral valve is clearly abnormal. Now, the exact nature of what the abnormality is at the valve is very hard to determine. [He ended with:] Very often the diagnosis of the precise abnormality is made by the surgeon on the operating table.

Because David's breathing and feeding were more normal, surgery could be deferred.

Cons: It's a question of considering the optimum timing for intervention - almost the later the better. If the child has mitral valve stenosis, then the options are really to do a mitral valve replacement if possible. The youngest we have done here is at one month and he is very, very well. He's clearly not - ideal, haemodynamically, there's obvious obstruction still, but the child is well. [] I didn't say I wouldn't have it done for my child, but that I would think very carefully about it and be not at all sure because it did mean a series of operations. []

They're very difficult parents, er, very nice, highly informed. I was amazed at how rational they were under this crisis but it was very difficult. They kept asking such straight questions. I think I want to answer questions that will help them to understand. But when they ask these difficult questions, I don't know, and I have to say, "well, maybe". I don't think that helps. They are highly intelligent parents and know what to expect.

After he had spoken more about the difficulty of diagnosis before surgery I asked again whether parents could ask surgeons not to replace valves. The consultant emphasised the need for careful medical discussion, ending:

Cons: If there's a valvar problem we will do our best to attempt to replace the valve.

PA: Mm. And do you/

Cons: /and that discussion should come up. [] We have problems [and he described 'last hope' surgery in neonates and went on to mastectomies, which he thought were 'identical' in that the patient consented both to a biopsy or a mastectomy depending on the surgeon's decision.]

If you felt it was technically feasible and a reasonable thing to do, even if it had a very uncertain long term future, I think you'd find it very hard not to do. [] One aims, with the hope of not having a child who's going to spend most of their childhood sick.[] One would think very seriously about whether this was a, a viable option. [] But no one can tell what the long term effects are of many of the operations we do. It may fall to pieces, and you can't guarantee where the child will come in a range of success, even whether the child will be better after surgery. I don't believe in the word 'cure' for heart surgery [and he described the risk of future problems.]

Senior registrar: [Who had come in a few minutes earlier] I wouldn't agree to a mitral valve replacement if it were my child.

Cons: A lot of operations are on that grey scale. [He listed surgery he would accept for his own child, but did not mention any operation he would reject, although he said:] But I'm not sure of some of the more complex things we do, how I'd react as a parent. [] Dr S who follows up our

cases into adolescence always talks about 'early triumphs and late disasters'. I think it's very important to see neonatal treatment in that context. We think the things we do are marvellous now, but whether they're going to be marvellous in ten or twenty years time is another matter.

Doctors would often begin by talking confidently about their work and slowly would become more pessimistic, suggesting the problems for them of making connections between clinical work and its effects on families. The tension between medical and parental knowledge and responsibility to the child, together with medical uncertainty was further explained to me by a surgeon. (It is difficult to describe the mixture of commitment, energy, and concern, mixed with humour and self-critical awareness with which the cardiac teams worked. One indication is a small plaque in the surgeon's office saying, 'We do precision guess work here.')

When I asked a question, as with David's cardiologist, the surgeon at once sat down and talked very fully and honestly.

He explained that sometimes the only way to know whether a valve could be repaired was to start cutting it. 'If it starts to leak catastrophically, usually you can't put it back where it was. You may find that the only way to get the child off the table, [i.e. to survive the operation], is to replace the valve.' I asked how he would advise parents. He replied that after the JCC he would have a long talk to see how definite the parents still were when the difficulties had been very carefully assessed and explained.

'And then you would perhaps only go in on the understanding that you may have to replace the valve. I think it comes down to: would you do it to your own child? I go home and look at my kids and I think about it a lot.'

A viable option

Mothers in the above examples talked specifically about the child's missing school or discomfort or disability. Doctors tended to talk abstractly about surgery as a 'reasonable' or 'viable' option. This approach can lead to assessing surgery for technical feasibility, whether a new valve can actually be fitted, instead of whether the valve will harm or benefit the child. Doctors are obliged to encourage faith in modern medicine.

David's cardiologist wants only to answer questions clearly and positively. He lists the operations he would allow for his child but does not say which he would reject.

The surgeon just quoted told me that the difference between people's relations with, say, a bank manager and with a doctor was fear, fear that they may be hurt or may die. He wanted to try to redress this imbalance through sharing medical knowledge in a reassuring way. So his information was influenced by his own reservations yet enthusiasm.

Surgeon: I'm very much in favour of transplantation. Cardiac transplantation is here to stay for sure, the results are good and they're getting better. [He mentioned extra problems of transplants for growing children, with the long term use of toxic drugs.] Transplantation will become so routine we won't be questioning the ethics of it. [] So the stress will be less because the kids will be great afterwards. If you like, we've already done over 400 heart transplants here, because we use homograft* aortic valves taken from a cadaver donor. I mean those kids are running around normal. I'm not yet sure of the risks because we're just reviewing the results but the risks seem to be very low for homografts. You have a very high risk if you put in dacron or plastic or metal. [] It is difficult when you bring the age down. The potential benefit becomes more complex, short term risk versus long term benefit. []

As they talked, both doctors became more hesitant about assessing the benefit of their work, such as by connecting it with the experience of families. Utilitarian values of measuring benefit by quantity not quality, and current political Griffiths attitudes, which value economic saving above the benefits to patients of life and health, tended to undermine medical confidence in the benefit of their work. The surgeon continued:

'But who am I to judge the value of what I do? That's up to public opinion and the media, that's reality, and the politicians we elect to make value judgements about what is worth funding.

In my whole life, I'm going to save less children than die every five minutes in Ethiopia, and [] these have all got twisted hearts. I'm doing this because I love the kick I get when the children get better, because it's technically satisfying. But its value in a world sense is very questionable. I generate handicap - to a mild degree and it's better than dying, but it is still a handicap. It's a cost to society. [] There is no doubt that open heart surgery is not as safe as we think it is.'

Connecting medical and family knowledge

Two questions raised by the examples of Tom and David are: how much should parents share in surgical decisions? and, should operations be performed which may sustain an intolerable life? Both questions have much to do with values as well as with science. When doctors regard these questions as medical but not moral, they may see them solely as professional judgements, outside the jurisdiction of the parents. Basic moral dilemmas can get lost in a mass of medical percepts. Discussion then shifts from *whether* an intervention should be made, to *how* it can be made, so that the validity of the intervention may be assumed before it has been fully considered. The living experience of the child and family, their values, the basis of their lives may then be ignored. One cardiologist 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.'

Yet dilemmas involve values. Parents varied greatly from wanting any treatment that might extend life, to thinking that their child had suffered enough, or wanting to be more certain that benefit was likely to outweigh harm of treatment. Down's children with atrioventricular septal defect* provide a range of examples. Some parents did not want potentially life extending surgery, because 'about twenty years may be the best for her. We know then that we'll always be there to look after her'. Others did not want to intervene in the natural course of disease but to leave the length of life 'to the Creator'. Some parents wanted their Down's child to live as full a life as possible. 'Of course we want her to have surgery. Your late teens is just the time when you are branching out. It's difficult enough to get a job if you're handicapped but impossible if you are sick too. We want as much for her as for our other children.' Other parents thought that their child had been unlucky and therefore should have extra benefits, including surgery if necessary, to compensate. Two mothers spoke about their bitter regret and years of depression that their child did not have surgery in time, and two others told me of their 'battle' to find a hospital where their child could have surgery after at first being

refused.

There is a tendency to base medical decisions on estimates of the child's physical health, setting aside mental health. Further, doctors are calculating ever more precise measures of physiological activity in laboratory tests, moving away from recognition of the living, everyday person. Increasingly, as medical trust rests on scientific assessment, less trust is placed in the opinions of the family and involvement with them. Social matters are sometimes said to be acceptable in GP work but not in highly technical medicine. Yet many, if not most of the children had defects which (so far) could not be wholly cured, some had months of illness. Their families were not looking (in Gilligan's words, 1987:42) only for 'the heroism of cure', but also for the 'vulnerability of care', that doctors risk the difficult work of becoming involved with families in order to help them to cope practically and psychologically with chronic heart disease. Respect for scientific medicine can work in tension with caring for children; avoiding personal issues can lead to less appropriate decisions. At some level science and care, technical and social medicine, have to combine, the pathways meet, and the degree to which they converge affects the quality of informed consent.

CHAPTER SEVEN

THE INPATIENT CONTEXT 1. THE FAMILIES' EXPERIENCES

'When I trained as a nurse 11 years ago, the nurses did everything for the children. But now I am here as a mother, there are far fewer nurses and I find the mothers are expected to do almost everything. I think this is right, but we cannot care for the children properly if we are not shown where things are kept, or not allowed into the kitchen, or to stay with them at night.'

(Mother in one of the cardiac units)

Parents now share in caring for their child in hospital far more than in previous decades. Yet doing tasks does not necessarily mean also sharing in informed decisions about medical care, or even about parenting care. Voluntariness and unwillingness in proxy consent to surgery are elusive qualities to observe. They may perhaps partly be indicated by parents' estimates of how much they are respected, involved or excluded as part of the decision sharing team. The quality of respect for autonomy may be indicated by the respect with which individual children are treated and the flexible ways in which parents are able to answer their needs.

Literature on consent often omits the context of particular hospitals and varying patient-staff relations. Such abstraction can help to arrive at conclusions which are not too cluttered with personal details and which can be usefully applied in other cases. Yet ignoring the setting can obscure crucial elements in consent. The social context influences the proxy consent process in: the *amount* of discussion, (how much parents can be present and can speak); the *quality* of discussion, (whether it is free or constrained); the *content* of what is discussed (the choice of medical and social issues).

This chapter reviews the social context of proxy consent. First, using examples of the physical space allowed for parents, possible influences on the mental space allocated to parents in the consent process are examined. Second, the contribution to the consent process of staff responsible for non-medical care is considered. The third section describes surgery as a set of practices to which parents may give qualified proxy consent. The final section considers examples of formal consent and of

nonconsent. It questions the nature and purpose of current consent practices.

Space

The hospitals' design did not encourage involvement of parents. They were both Victorian buildings, with little space for amenities for patients, staff and relatives. Both were in parking meter zones with no car parks for visitors. Many of the patients were small babies but neither specialist hospital had a maternity ward. New mothers were tired by the long distances they had to walk to the canteen and their bedrooms.

The four wards I observed will briefly be described to suggest connections between the space and design, the routines and rules and their effects on parents' ability to take part in decisions about their child. Each hospital had an intensive care unit, (referred to as ICU), mainly for intensive postoperative care, and a ward (referred to as ward) used for admissions, investigations and convalescence. A children's ward is a cross between a home and an institution, a nursery and a laboratory. These working purposes were combined in different ways, resulting in a very different atmosphere in each ward.

CH ward with 10 beds was cosy and homely. There were no offices and families used every room freely. The sister said she spent 95% of her time talking with them. She talked to me about parents in the ward kitchen while sitting on a bean sack with an eight year old girl on her knee.

Sister: Sometimes, if the supper trolley comes up and there are crowds of people in the kitchen I say [mock anguish] "Please, everyone out! I can't move."

Girl: [In pretended outrage] You can't say that!

Sister: You have to be jokey and have a good rapport and not make serious rules. But we're small here, we're lucky.

The sister seemed to respect and trust parents and to consider it worthwhile to share care with them. She suggested that parents had a responsibility to question medical decisions.

Sister: They love helping, especially if their child is ventilated on ICU. They come and chat here and are very positive if I ask them to feed a baby. [] People are so rarely aggressive here, only if they are under great

pressure. They accept all sorts of things being done to their child. Perhaps they don't question enough unless you force them to question.

HH ward's senior sister acted mainly as the administrator of a very busy 24 bed ward. People passed almost constantly through the ward. There were offices at the far end and several locked rooms including, at set times, the play room. There seemed to be invisible boundaries drawn round each cot and families seemed reluctant to venture outside them. There was no neutral, quiet, comfortable area for families to sit. They were timid about going into the play room and some would ask my permission to enter if I was alone in there. Often there were too few chairs. Some parents would sit on the floor rather than move a chair from another room. The orderly would not let parents use the kitchen. The sister said that she could not help this, although her successor opened the kitchen to parents. The new sister also made the admission time later so that families no longer needed to arrive in the rush hour and sit ignored, squeezed by the door for hours waiting until patients were discharged and beds were free. Later the ward became a more friendly place as new sisters made changes, but at first it tended to be an impersonal workplace where families seemed to feel uneasy.

CH ICU with 20 beds was a tense place. The nurses contended with many problems. It was a through corridor. Many children and staff were cut off from one another in tiny rooms not designed to hold all the machinery. The 'pump room' with three beds for the most ill patients had little spare space. Parents would stand in the corridor looking in through the window. The frequently empty kitchen had a notice forbidding parents to use it as there was 'no room' for them. Some nonintensive care children who could not be fitted into the ward were in ICU and the busy staff had little time for them. There were many student nurses so that trained staff had heavy supervision and skilled nursing work loads.

HH ICU, in contrast, was modern and spacious. The staff office overlooked most of the unit and cots were mainly in two large rooms with plenty of space for parents and staff to sit beside them. The unit design seemed to encourage friendly and relaxed relations between staff and families. All the nurses were qualified, there was at least one nurse on duty per patient.

Expectations of parents

There appeared to be an association between staff's expectations of parents and parents' sense of their own value and competence. At HH, new mothers were encouraged to stay and ICU sisters spent hours arranging for midwives to give the statutory cover. They also arranged for a hot drinks dispenser and a second small parents' sitting room for breast feeding mothers. Their care showed the amount of time and persistence needed in working to provide facilities for families. At CH there seemed to be less enthusiasm for new mothers to attend. Several told me that they were advised to stay away for the first week or more until they 'felt stronger'. Parents talked about the problems of being separated from the baby.

Father: When she was two days old she was suddenly transferred here. A policeman came to the door at 2a.m. to tell me. There was no transport. In the end I ran to our local hospital. They told me she had no left side to her heart. It was probably hopeless.

Mother: I don't think they should have said that to us. It wasn't true anyway. They woke me up and said there was something wrong with my daughter. Then they gave me a shot of valium. For the next few days I was living in a world of my own. I didn't understand what had happened to her, or anything. I wish they hadn't done that. I'd like to have come with her. I wish they had a maternity unit here, they have so many little babies.

When I came in to see her, I only had a glimpse. I nearly fainted. I was told I shouldn't have come because I might haemorrhage as I was so upset. I went into a waiting room and cried, then I went home. I was in a filthy mood, so angry.

Other parents found that they were kindly treated but still felt that there was no room for them. One mother said that when she brought her two day old baby:

'The surgeon brought us tea and made sure I was reclining comfortably. He talked to us for a long time and impressed on us that caring for the baby meant caring for the parents

too. We felt very grateful. [] We understood that we couldn't go in the pump room so I decided to stay at home.'

Differences between ICUs at the two hospitals provided vivid examples of contrasting influences on parents' expectations of their own abilities, and how these could affect the quality of informed consent during the continuing treatment of the child before and after surgery.

In CH ICU there were no formal restrictions but parents tended to stay in a small sitting room just outside the unit. There were unofficial barriers. Many parents had to wear white gowns, although these have been shown to be useless as infection barriers, (Forfar 1958) and are no longer used in many ICU. Communal gowns seemed likely to encourage rather than reduce cross infection and worried some parents, who told me, 'They make you feel that you are too germy.' The nurses were often too busy and seemed too tense to talk. 'You feel frozen out by their attitude in there.' The play worker, in some ways the parents' main helper, also discouraged access. Like the kitchen orderly in HH ward she saved senior staff the trouble of explicitly enforcing rules which were convenient to them. When we first met she told me:

'When their child's on the ventilator and doesn't need them, parents stay all the time. When their child really needs them, they're out shopping. They're not allowed to sit in ICU. There's no space if a nurse has to pounce on the kid straightaway. It's harder to read the machines. The consultants don't really like it. And it's awkward if parents are there and something happens.'

In CH ICU many parents had lower expectations of their own ability to help their child.

'Of course it's tense in there, that's why it's called intensive care. We can't do anything for her, she's completely in other people's hands and the days are very long. I'd like to stay in there and come out every 30 minutes for a fag for 2 minutes. But this is the wrong way round. We stay in this waiting room in no-man's land.'

'Everyday I'm used to dealing with problems at work. Here you feel totally inadequate towards your child, helpless, just waiting for the next step.'

Without help and encouragement parents are liable to remain in their initial shocked state of first seeing their child in intensive care. At CH many would talk about their fear of the equipment.

'I still haven't come to terms with the awful shock of seeing him in ICU. I feel that it's a dead body, plumed into everything, immobile. I don't think you can become involved. There's nothing you can do you're just blocking up the way.'

'I'd just be in the way. Things often go wrong and that would make me panic. I'd rather not be there when they're rushing around. So I go to her for five minutes every hour but I don't want to leave the hospital. But if I sat with her, I'd get hypnotised by those heart beat machines, neurotic about them.'

'You feel very much in limbo. As long as they're really wired up there's nothing you can do. I wish we could use the kitchen here. I don't like going too far away even if I can't be with him.'

'They're very good at explaining. If you don't ask, they'll think you don't want to know. But when you're upset it goes in one ear and ... you can't take it in. The pump room's got the most up to date equipment, marvellous machines, but you don't like to go around searching for a chair, so you say, "Oh, excuse me", and you leave. There's no room for you. That adds to the tension and the trauma.'

If parents felt helpless it could be harder for them to be hopeful. This mother in CH felt at a distance from her child in intensive care, as if she were already taking leave of him.

Mother: There was a 25% chance he would die. I began to imagine what the future might be like without him and I decided I wouldn't have another one, and risk putting another child through what he's been through.[1

PA: And you have three children?

Mother: No. Well, yes, but not if he...

Parents were discouraged by informal barriers at CH.

There were formal barriers in HH ICU. Parents had to ring an intercom for permission to enter and they were sent out during medical rounds, xrays, physiotherapy and emergencies. 'You seem to spend so much time hanging about in that little waiting room,' was a frequent comment. Yet once in the unit, most parents seemed to feel welcomed and encouraged to stay because of the

personal concern shown by the sisters and nurses. At HH, a father said,

'The ICU nursing staff see our child as an individual. They have a very caring attitude. They're very flexible, no matter what you ask. There isn't this cut-off thing - "No I can't help you." They're very accommodating.'

Parents spoke of the importance at HH of being able to sit with and comfort their child.

'We can stay as long as we like, except for the rounds.'

'I'm sure it is very important for him that I'm sitting here, stroking him and going through it with him.'

Parents' certainty that their presence helped their child, and the warm encouragement they had from HH nurses enabled them to cope with their fear and horror at the intensive care equipment and atmosphere. Sitting with 'their' nurse most of the day gave them time to learn and understand. Very few parents remained so disturbed that they stayed outside the HH ICU.

'The nurses are very loving and caring.'

'The nurses were excellent in every way, very informative and polite, I was very pleased and impressed with them all.'

'They are wonderful, so busy but they help you all they can.'

Consent to surgery involves consent to many nursing and medical procedures. This section suggests that parents' confidence and ability to share in nursing care is influenced by the expectations of the nurses about their ability. In this study, parents seemed to give most general nursing care, including caring for other people's children, in CH ward which appeared to be the most welcoming of the four places. They were most likely to intervene in intensive nursing care, such as to ask for pain relief, in HH ICU where they felt welcomed and respected by nurses who had time to talk with them.

The quality of consent, being linked to parents' sense of freedom to talk with the staff, is likely to be influenced by the attitudes, accessibility and availability of the staff. Doctors

tended to be accessible in HH where their offices were mainly based in the ward, rather than in CH where most medical offices were in a separate building. However, parents usually thought that access was very different from availability, that just seeing doctors did not mean that parents felt free to ask them to stop and talk. Parents were aware of invisible barriers when doctors looked in a hurry, avoided looking at them, and left quickly after concentrating on tasks. Many parents considered that the most important factor in communication was how available or approachable professionals seemed to be.

Mother: Some are more approachable than others. When you've been in here for a time you learn who to ask. When they come round in a group you feel in awe, a bit frightened, you don't want to ask then. Later, I would ask Sandra [senior registrar].

PA: Why would you ask her?

M: I think it's easier because she is a woman. But she acknowledges you too. She'll smile and say, "Hello," if she sees you in a corridor or the canteen. The others don't look at you. It is easier to ask the junior doctors, although one of the consultants is approachable. You feel that if you don't understand you can ask him again. But we're not always lucky enough to see him.

As in the clinics, doctors discouraged contact partly in order to hurry through a heavy work load. Whereas doctors would attend a patient for a specific task and then leave, nurses usually remained with their patients and were therefore more accessible and available to talk. Nurses were important mediators in helping parents to gain access to medical time, by encouraging parents through respecting their views, by talking to doctors on their behalf, or by arranging for doctors to talk with them.

Anxiety and awareness

Individual doctors and nurses were highly praised for their kindness. Yet the doctors seemed to concentrate only on medical care and information. They left practical matters of access and accommodation to other staff as if these did not connect with medical care. However, especially in emergencies, parents were less able to think about surgery when upset about the accommodation which forced the family to separate when they needed to be together. One father described to me the conflict

between information about technical details and awareness of the whole family emergency. They had rushed to CH with their two day old baby 'feeling that we couldn't bear to look at her. [] She was struggling for breath, obviously in some discomfort and screaming.' When they were told that only one parent could stay overnight near the unit, his wife was very upset. Later a surgeon arrived with the consent form.

'I gave permission and didn't give it a second thought till afterwards. There was very little soul-searching. It was essential, once they'd explained it to me. Afterwards, I imagined the gory details and felt more uncomfortable. You think about your child and the knife afterwards, but at the time you're happy to agree.

It happened at a difficult stage when you [looking at his wife] had gone to the dining room in tears and I had just gone up to tell them we wouldn't stay. And they explained with a model of the heart. They asked me where you were. I said you were upset and told them to carry on. The surgeon said did I know about the working of the heart. I said, "Yes," hoping I'd remember O level biology. I was conscious of wanting to be back with you, so I didn't ask as many questions as I'd normally do.'

Taking time during an emergency to explain carefully with a model indicated concern that parents should be as fully informed as possible, showing a respect well beyond what was legally required. This respect emphasised reason, expecting parents to set aside anxieties in order to concentrate on rational explanations about surgery. Yet consent is a thinking and feeling process. Feeling is a necessary prelude to awareness. The father suggests that he did not absorb or 'give a second thought to' the technical knowledge, like 'O level biology', until later when he had 'qualms'. Qualms could be seen as unnecessary sentiment, or else as responsible awareness, unlike a glib unthinking signing of the form. Recently shocked by the distress of his daughter and his wife, the father might be regarded as being in a state of heightened awareness, a form of knowing which is different from mechanical understanding of the purpose of surgery, yet an empathy which is perhaps essential for valid proxy consent.

The parents' need to remain together near their child in this crisis could be regarded as positive and responsible, the kind of strong family concern which is essential for the child's

wellbeing. If the need was recognised and valued by doctors and administrators, if they listened to parents and respected the rational causes of anxiety, hospitals would be reorganised to provide reasonable space for both parents. No longer distracted by unnecessary worries about separation, parents would be likely to learn more from technical explanations. Their feelings could be respected as part of their growing awareness instead of being set aside in order that doctors could 'carry on'.

One large issue in consent which I have not considered in this thesis is consent to emergency surgery. This omission is partly due to lack of space, partly because protracted discussions reveal more of the consent process. I will just briefly mention here, that shock is often given as a reason for parents being unable to give rational, informed consent. However, it is important to distinguish between shock about the baby's condition, and shock about the means through which surgery is provided, such as by separating families, or the harrowing journey for parents following behind a speeding ambulance. In many cases, the latter kind of shock could be considerably reduced if new arrangements were made. The former kind of shock, even temporary numbness, as discussed earlier can be part of growing awareness.

Hospital policy

Both hospitals were in special authorities, separate from the NHS regional networks. Neither had a district health authority, community health council, or well forged links with local newspapers and community groups. So the dialogue was missing which most hospitals have with the lay community they serve. This dialogue can exert strong positive pressure on issues that concern patients such as amenities for patients, relatives and staff. It can also show certain patients' 'complaints' to be constructive suggestions for improvements, and the expression of responsible public opinion, not of an ungrateful minority.

One effect of not having a firm 'voice for patients' was that medical and administrative interests predominated and absorbed almost all the resources. In comparison, nonmedical amenities for patients and staff seemed far poorer than in many local

hospitals. Next door to CH's pump room was a very large, mainly empty room. Eventually this was converted into cubicles. If they could have been used as interview, sitting and bedrooms an enormous amount of pressure and fatigue could have been relieved in the ICU for parents and staff. They were used as offices for another department.

Local newspapers run features about improving hospital amenities, local groups donate funds and constructive changes are made. However, the national media present these special hospitals as centres of technical medical excellence implying that social care of patients is adequate or unimportant. One father, a film camera man, said in CH:

'All the TV documentaries about this place don't put it into perspective. They just select the quirky things, the expertise and know-how. I feel angry that the level of care people need is devalued.'

He went on to describe with admiration the care which he thought was given almost despite the authorities but which, he thought, they should value and support.

'Some of the nurses build bridges, a hand on the shoulder, right words at the right time. Like nurse Stephanie who sat and cried with a mother. You can't measure that.'

Many parents were concerned about the mismatch between excellent medical care and poor conditions which increased their distress at a time they could least cope with added stress. They were reluctant to criticise matters which seemed trivial yet which affected them severely. A mother in CH said:

'The medical care is fantastic. They explain every little thing to us. They've saved my lad's life, what more could you want? But I hate the hospital. It's stupid little things missing. They told me to go out and buy him a bottle and teat, they don't have them. There aren't enough bathrooms, and no toilets on this level. We have to go downstairs and I dread that at night. The phones don't work and I'm running up a fortune in reversed charge calls to Norfolk. All sorts of things are missing you take for granted, and it makes you very uncomfortable and anxious.'

Joint consent was a luxury some parents couldn't afford. Interruptions to put another 10p in the phone turned the difficulty of explaining complex surgery into an impossibility.

Listening to parents

When parents talked to me about their difficulties they often said, 'I hope you'll be able to use what I say to help other people'. I thought that if I did not try to pass on to the staff some of the criticisms, that, in a way, I was helping to support conditions which created problems. Inevitably there is a moral dimension to this research, because informed consent is tied in with harm and benefit to relatively helpless people. By listening to the staff and parents, in a sense I was already intervening, and was therefore having some effect in processes which could harm or comfort. I was also working with methods which valued engagement and efforts at equality with the research subjects. When researchers submit a report after leaving the place of research, there is unlikely to be much effect, since the hardest part of change is not to report the need for it, but actively to work for it with those who find the time and energy to do so. Yet overt intervention by a researcher creates difficulties. It furthers contacts and knowledge of the hospital in some ways, but partly closes it in other ways. For example, some of the nurses wanted to listen to patients' views and worked hard to make changes to benefit families. Others thought that criticisms were unrepresentative or untrue. When I said that the parents needed somewhere calm to sit in or near the ward, a sister said to me:

'You make it sound as if the parents are being so controlled. But it's not like that. If the idea had come from another sister we'd have accepted it more easily but you don't understand, and we were upset. You said parents hang around the corridor but they don't really, well, they do but ...'

Other kinds of staff responses to proposed change have been listed in chapter 4. Some hospital staff did not seem to see patients and relatives as able to contribute useful ideas. For example, they saw parents' meetings as useful for staff to teach and support parents, but not to draw on parents' expertise to

help to plan better care, routines or meals for the children. As a result services for families were not always based on families' expressed needs.

One example is the fairly new house for CH families. This was greatly appreciated by a few families and answered an obvious need. Yet in my parents' survey, (attached p13) most parents in both hospitals wanted something much cheaper and easier to arrange, - to stay in or near the ward. They were frightened of walking through London at night and through a tunnel into the hospital, and were worried that nurses would not call them if their child woke. Probably more people wanted to stay in the hospital than indicated in the survey, because in my interviews parents often said they did not want to stay at the hospital. They then explained that they would want to stay, and did so in their local hospitals, but at the cardiac units they found the accommodation too depressing, ('it's near the morgue'), or too lonely, ('I need to be with my husband during this crisis,' 'I just can't cope on my own',) or too far from their child, ('so what is the point of staying?')

A nursing officer at HH told me:

'Parents leave the place looking like a pigsty. I've had to throw out a lot of those folding beds we were given for them. I am not having them staying on the ward over night and that is final.'

Many parents and junior staff disagreed with this attitude as shown by our nurses' survey (attached). A mother at CH said:

'I went back later in the evening and found he was so worked up they had to give him a sedative. He's six months and he's terrible, so clingy. They said they'd call me if he got upset. I thought, there's no reason to let him get upset! As soon as he woke I could have got him to sleep, and there's no way I'll leave him now. By midnight I burst into tears and said please don't make me leave him. The nurse said she'd get into trouble if I stayed, but she sat talking with me for 2½ hours explaining all about his operation and all the tubes. I thought it was marvellous. Then she let me stay in his room on a bean sack.

I know it's a fire risk, [this was one reason given for not having parents in at night] but Edward would have been safer with me there to carry him out. I wouldn't have done anything to get that nurse into trouble, but she got a speaking to and afterwards she said that she told the nursing officer that she goes for the psychological effects on the mother as well as the baby if they are separated. I

thought, good for you. What's the point of getting us upset? She said if she had half a chance she'd have mothers staying.'

The accommodation officer in each hospital was concerned that there was not enough space for everyone who needed to stay. One told me she had drawn up detailed plans for using more hospital flats for parents.

'We need a dormitory for fathers. But it came to nothing. The administrators wanted the rooms for offices. They don't understand the need. Some fathers sleep in cars. Others are paying £36 a night for bed and breakfast, and living on snacks in order to manage. People from Cornwall are terrified of being in London. If they are on supplementary benefit only one parent is paid for so the father can't come at all, and often they are not on the phone. If the child is very ill they need to stay together. Ten double rooms could take care of the problems. I have to juggle and switch people around. It's a desperate situation. If they knew the despair I see I wish we could be more flexible, and I think letting rooms could pay for itself with the contribution from parents.'

The parents found the officers usually kind and helpful. In my interviews, lack of space to stay near the children was the most commonly mentioned feature of the hospitals which caused parents greatest distress. The officers and parents were caught in the gap between supply and need. The officers tried to be fair and tactful, but sometimes fraught parents had rows with them and they resorted to defensive rules. One said,

'We've had to say only one parent can stay. We used to have two, but sometimes other parents would come and rage and demand. Making allowance for some just became impossible, and you get the 5% who abuse everything so badly.'

Most parents just accepted decisions. For example, one evening I was near some parents who knew their baby was very unlikely to survive. An officer phoned the unit to ask the mother to return her key as someone else needed her room. The mother agreed saying to me, 'What does a key matter at a time like this?' She had no energy left to argue. Sometimes doctors or nurses intervened, asking the officer to arrange for one or both parents to stay if a child were very ill, but often they seemed too busy to know about, or be able to take on, these matters.

Access and consent

Parents' need for accommodation near or with their child may seem remote from informed consent, but here are some examples of how the two can be related. Adult patients are able to consent or dissent to procedures because inevitably they are present, and usually conscious. Parents have to arrange to be with the child in order to be able to know what interventions are proposed, and to give or withhold consent. For this, non-resident parents have extra difficulties, partly because the staff are less likely to see parents who have to be absent as having an integral part in preparing, comforting and caring for the child. 'You have to watch out all the time,' said one father, 'or you turn round and find they've done an injection or taken him to xray.'

Many parents wanted to give or withhold consent to interim details in their child's daily nursing and medical care. A confident adult patient might make requests, for example, for pain relief. Parents wanted to be present to do this for their child because the child might not be able to ask, or might not be heard as an adult would be, and because children can be more frightened than adult patients. For example, parents wanted to ask if a drug was necessary or that an xray be delayed while it was explained and the child was prepared, or allowed time to recover from some upset. Parents acted as two-way interpreters between the child and the staff, explaining the child's needs to the staff and the staffs' actions to the child.

Parents were also necessary mediators between the immature patient and the potentially overwhelming contact with a range of strangers. Parents filtered and partly controlled experiences to help the child to cope with them. (Robertson 1970, Jolly 1978) One mother wanted to stay overnight with her eight year old who was on a drip and was upset because she could not get to the toilet in time when she was unable to get a nurse to hear her calling for help. A thirteen year old told me how for years she had had to think about how her heart was beating and to guard against over exertion. After her operation she listened to all the bleeping heart monitors worrying that one would stop. Like many children she was frightened at first when moved out of ICU and the full-time care of one nurse to the short staffed ward.

She was afraid to go to sleep unless her mother was there because she had started to have irregular heart rhythms and was waiting for a pacemaker. The mothers were not being overprotective; they knew how much stress their child could cope with during admission and their main concern was to help to prevent avoidable distress.

Uncertainty about being 'allowed' to stay with their child, added to parents' anxiety and sense of helpless dependence on other people's decisions concerning their most basic needs. The imbalance of medical to lay knowledge was reinforced by inequality of control of resources in matters which most closely affected parents' status: their right of access to their child and recognition that their child needed them. This had repercussions on attitudes and practices in the wards. Nurses who wanted to work in family centred children's wards were distressed at having to make parents leave and were not attracted to stay in the cardiac units, as shown in our nurses' survey (attached) and discussed at nurses' meetings which I observed. Half the children's nurses left HH during 1986 (for many reasons including conditions of work) and the CH cardio-thoracic unit was even more short staffed and for a time had to refuse all emergency cases.

While some nurses were angry that parents could not stay, others were influenced by this part exclusion to think that the hospital's right over the child increased. Talking of a baby who had lingered for weeks in the unit and died in theatre, a group of nurses debated whether, in the parents' position, they would have consented to almost certainly fatal surgery. Some said that the baby would have died anyway, and at least knowledge gained from her operation might benefit future children. One nurse said of the parents,

'She was their baby, but who cared for her? We did. She'd never been home. They knew they owed a heck of a lot to the hospital.'

This comment could be interpreted as implying that the parents had a greater than usual obligation to agree to medical advice, and that hospital staff, who provided almost all the child's care, had the right or duty to a stronger influence in decisions about the child.

Families already felt this obligation strongly in a positive way, that they 'owed their child's life' to the hospital. 'We thank the surgeon for giving us 20 months with her,' said one couple, after their daughter died. Gratitude made many parents eager to support medical research on their child, 'Anything we can do to help others, when we have gained so much.'

When the child received, not medical care only, but much parenting care from the staff, the parents' sense of obligation could be further complicated by feelings of guilt, inadequacy and jealousy, 'He'll only take anything from the nurses in ICU, he doesn't want me then - or afterwards,' said one mother in CH. Another said, 'He hates me for what I let them do to him. I've got to bring him back in three months. Every day I dread that and don't know how I will do it.' Many families needed help to come together through the crisis of surgery, rather than being split further apart by hospital policies which could cause distress and guilt, and to which parents could feel forced, unwillingly to comply. Daily hospital routines can help to show the kind of respect shown to proxy patients and their degree of freedom to negotiate. Routines are part of the context and the content of the consent process.

Parents and professionals

Ann Oakley once asked nurses why they wanted to be professionals - people who had a long, arduous training which distanced them from their clients - instead of wanting nursing to be concerned with sensitive care within relationships of equality and mutual respect. (Oakley 1984) In the postgraduate teaching hospitals with their emphasis on professionalism, academic status and hierarchy, the nonmedical staff reacted in three ways. One way was to resist ambition and status and to provide friendly, sympathetic support as, for example, many nurses, secretaries and the HH playworker did.

The second way was to create their own area of expertise and authority, and some staff were rather pressured into doing this. For example, parents' first contact with one ward clerk often was to ask if they could stay. The clerk replied by saying that there was no room and it was not necessary for parents to stay.

This set a barrier of authority between the clerk and parents who disagreed with her, and raised problems of rules and obedience, and of undermining parents' own knowledge and authority. Play was not valued at HH and nursery nurses, whose specialty was play, were used as unskilled nurses and seldom played with patients. They developed their own area of authority in a milk kitchen, locking themselves in there for an hour a day to wash the babies' bottles. Left empty for most of the time, this room could have been used for other much needed amenities, such as a quiet interview/sitting room, a doctors' office, or a school room. One effect of the nursery nurses' supposed expertise was to imply that parents could not wash their babies' equipment. Another was that parents who found the room locked thought that they were not allowed into it. The nurses then had more work fetching feeds and mothers tried to calm their babies until they were allowed to feed them. Confident mothers, such as this well-known actress, spoke in child-like terms.

'I never know whether I'm supposed to ask a nurse for her feed or go in there and fetch it. Sometimes I slip in and hope no one is looking.'

A third approach was to use professional skills to increase families' ability to cope, rather than to control them. Different playworkers clearly showed all three kinds of professionalism. In CH play was valued and was used to help families to gain confidence.

Father: They spent a lot of time with us, starting with trying to tell the child, which was very educational for us because we then had to prepare ourselves to answer the questions she would have. The playleader gave her a book of photographs. She asked us if we wanted to see it first. We were a little anxious that it might be too much for Sarah [aged four] because up to that time she hadn't shown any fear, but we let her see it. I think she was a little upset by some of the pictures. But then the playleader asked her if she wanted the teddy who'd had open heart surgery. So she dressed up as a nurse and put on a mask and the playleader worked with the teddy and showed her all the tubes.

Mother: She worried like anything when she read about the injections, that she would have two and it would hurt. The book said it honestly. But finally, after the playworker let her actually give a real injection, you know using the same needles as the nurses do, to the teddy, doing that over

and over again seemed to quench her fear. We thought we'd better read about it so we had the printed booklet which the sister wrote. It was very, very useful, though I think we learnt as much from the play book.

Father: It's all so simple, and more, - I think the way it's done, it brings you much closer to -

Mother: Yes, the human side. Somehow it's easier, reading through the book you know your daughter's reading. She's very inquisitive and she wants to know.

Father: I think this play and the nurses do more to get you psychologically prepared, how to cope with it. The doctors' interaction tends to be more technical, medical. You know, not in a sort of cold way, but - we felt prepared watching Sarah play.

All members of the unit team could influence how much parents felt able to be present and to relate on equal terms with the staff during the consent process. Nonmedical staff were responsible for easing the fit between medical and social aspects of care. They received and reported much medical and social information about the children, sharing this between the families and the staff. They gave social and psychological help to families and staff which tied in with the medical care. The next section considers ways in which the social and psychological care of families was provided and how this care, or lack of it, could influence the consent process.

Social and psychological support

Social workers offered two main kinds of help: financial and psychological which one of them described as 'help in sorting out the family's confused feelings towards the child, who through no fault of its own creates so many problems for the family.' The CH cardiac social worker's post was frozen by the rate-capped local authority for most of my time there, and very few families appeared to receive help. A psychotherapist attended weekly psycho-social meetings with the two senior nurses, two playworkers, and the social worker, if any. She mainly advised the staff, such as on 'how to get through to children they were worried about'.

A few parents in CH sounded so depressed about their problems that I suggested finding a social worker for them. They seemed crippled by anxiety and unable to ask for help. For example, a divorced mother, whose eight year old daughter after a long

cardiac arrest a week before suddenly had a mental age of about 18 months, had not known where to find money for the following day's fare. After seeing the social worker she said, 'I feel human again. The first thing, she offered me a fag and we had a really good chat in her room and she's found £80 for me.' Two parents looked ill with anxiety about their eight year old son who had not regained consciousness since his operation three weeks earlier. They were also worried that after weeks away from work they would both lose their jobs, but said they had not felt able to contact their employers. 'Losing the job would be nothing to losing him.' The ICU staff did not seem to be aware of these problems. Possibly, as they could not easily refer families for social work help, they avoided asking about problems which they could not alleviate.

The HH children's social worker could not answer all the requests for help. Increasingly she concentrated on the families who asked for her counselling support. Concerned about children's fear of hospital and of surgery, she started a therapy play hour for children, trying to involve nurses in listening to children instead of tending to dismiss their fears with 'never mind you'll be better soon'. Two psychologists doing research at HH thought that some form of psychological support was urgently needed.

The staff in both units varied in how far they acknowledged psychological difficulty in their work, or tried to ignore it. The social worker for a time ran separate support groups for parents and also for nurses to help them to *cope with stress* by sharing their anxiety and so overcoming some of their sense of isolation and inadequacy. (Alderson & Rees forthcoming). The social worker also tried to *reduce unnecessary stress*, for example, by raising funds to redecorate and furnish a formerly 'grotty, tatty old room' for quiet interviews. The aim was to help parents who thought that a private place to talk was very important, partly because of the distracting noise in the ward, the difficulty of hearing doctors, some of whom spoke quietly or in foreign accents, and the embarrassment of being overheard when asking 'silly' questions. Parents needed somewhere quiet to recover from bad news before returning to their child and the

public ward. The phrase 'sit down and talk' was often used by parents and staff to denote talking about serious news. It suggested allowing time and sitting face to face on an equal level. Yet this could only happen if there were spare chairs and quiet space nearby.

Not all parents wanted help in the hospital; some preferred to cope on their own. 'We dread tea and sympathy,' said one father, 'We'd rather go and make our own tea and cry on our own.' Parents who were very grateful for the kindness and care they received from the staff tended also to share warm, supportive relationships with other families. Both groups could be considered as managing in the way they preferred. However, from three sources, (observations, interviews, and my questionnaire for parents), it was apparent that some parents were very isolated, feeling that they received no support from other families, from the range of hospital staff, or from their own family. Some of those in greatest need of help seemed to be least able to ask for it.

Reasons for attending to parents' mental health during the crisis of admission include: to prevent the child suffering because of the parents' depression; to help families to cope with psychological and financial problems partly posed by centralising cardiac care far from many patients' homes; to help parents to avoid feeling overwhelmed in order that they can understand medical decisions. Like powerful drugs which bring great advantages but can have adverse effects, medical information could be a mixed benefit. It presented parents with knowledge and dilemmas which they often found extremely difficult to cope with. Parents' ambivalence about dangerous treatment could be a source of family turmoil. The HH social worker said of one family:

'It's very important that this decision is discussed fully with both parents. It may relieve a lot of their enormous worries. Last time Mrs W had to consent without the father being there and he was very angry. He's in a bad state now so it is essential, it's vital, that he is fully aware of what the next operation is going to be like so that Mrs W is protected in case something goes wrong.'

A sister told me:

'This 20 stone miner came charging into the unit furious with his ex-wife. She gave consent to a shunt operation and then at the last minute to repair on bypass without him knowing. She wasn't clear about the difference and the extra risk with the repair. The child died and now he's blaming her and contesting custody of their other children. He says she's not fit to care for them.'

It could be argued that if family discord is already present, possibly parents are looking for a factor to blame or to quarrel over. The hospital therefore need take no responsibility for the parents' response to routines such as signing the consent form. Yet it could be argued that prolonged family tension is likely to be closely associated with the child's heart disease. The whole topic of consent is very sensitive both in its direct meaning (committing the child into danger) and in its symbolic associations (the consent form assumes united parental responsibility for the child which may not be the case). For the child's sake, handling the potentially contentious matter of consent carefully may be seen as partly the hospital's responsibility. A third view takes voluntary consent seriously. However much consent is complicated by other family problems, the reason that it attracts guilt and blame is that parents can feel uncertain, angry and afraid about consenting to surgery. Further medical information can help, but many parents also need time to sort out their mixed feelings in order to achieve a state of mind in which they are reasonably willing to agree to medical proposals, their agreement becomes stronger than their doubts. This process can be so complicated that skilled counselling may be needed, as in the following example.

It could be difficult for everyone to accept a decision that surgery was too risky. Parents' growing awareness might be slow and complicated requiring more than straight medical information. James had spent almost all his 16 months in hospitals. He arrived at the clinic, still only weighing his birthweight. The consultant said:

'he is a very sick, floppy little baby. Very great pressure was put on us by the parents to operate. We put on a band,* now what can we do? There is no hope in operating. You

need to really sit down with them for an hour to talk about this. That's impossible in outpatients. We'll admit him.'

He decided that they should reduce the drugs and send James back to the referring hospital to die. The social worker was asked to prepare James's father, (his mother had left the family), to accept that there was no hope. She told me that she thought:

'Doctors tend to leave things open, they are not conclusive and clear when it is bad news. Maybe they feel they have to keep alive some hope, but their dilemma is that they can only offer something if they're convinced it'll work and if it's the appropriate thing, - not to be wishy washy.

I was told that everyone had agreed that James's father must be told that nothing could be done. Then I was asked to "sound out his father, to find out his feelings about this." Suddenly I found that none of the doctors would be there. This was mindblowing. I felt furious with myself for agreeing to take on something so difficult which I felt was really the doctors' responsibility.

So, I went in and Mr Brown happily said, "Oh yes, he's going to get better and they'll operate when he gets fatter." So I said, "I don't think you really know what's going on and I think you ought to see a doctor."

The social worker could only help Mr Brown to accept medical information about his son's future by listening with him to a doctor, not by explaining the prognosis herself. She asked an SHO (senior house officer) to talk to him.

'The SHO came in with me and he was very good, gently putting forward in a slow way what they'd hoped to do, what possibly could have been, but now Jamie wasn't growing it was cruel to give him surgery that wouldn't cure him, and drugs that wouldn't help, but gave him a rash. For about five minutes Mr Brown insisted the rash was due to the baby being allergic to the sheets. He couldn't accept the idea of bad medicine. I thought it was lovely that he was trying to keep up some kind of faith.

We went on, the SHO saying, "But Jamie isn't growing, Mr Brown saying, "Look, he's getting longer," and the SHO saying, "He's not growing." I said, "It's very difficult for you to accept that Jamie's not doing as well as you want." And that broke the escalation of their argument. It was good, the social worker and doctor working together. I interpreted the doctor's facts and the SHO did his good talk about the prognosis being poor. He only later used the word "die", and then Mr Brown went in for real denial, saying, "Yes, he'll have surgery later and he'll get better and be running around." SHO: "No he won't." Me: "You really need to hang onto that hope that he'll get better." Mr Brown: "Yes. You don't know definitely he'll die. Who knows that?" as if he felt quite impotent. You need to have some

element of control in the destiny of your child. When a doctor says, "He'll die," a bit of you wants to say, "No. no. He's mine." Then at the end, the SHO spelt out, "Jamie is going to die." Mr Brown said, "Yes, I've known for a year - but he's going to live." It ended with nothing settled.

A question for nonmedical staff was how their work fitted in with medical work. How much should they act separately, or 'obey orders', or share in and try to influence the medical work? Some doctors were described as appreciating the value of, and referring patients for, psycho-social care, discussing patients on fairly equal terms with nonmedical staff, listening to their views, and taking these into account. Nonmedical staff thought that their work was more effective and patients benefitted when medical and social care were combined in this way. 'I feel interested and committed, almost dragged into his team. My insights are used,' said the social worker of one such noncardiac doctor. Cardiologists tended to concentrate on anatomical defects treated surgically in acute crises and seemed less interested in chronic and psycho-social problems. A psychologist in one cardiac unit said,

'They don't often make referrals I feel there must be so many children and parents in distress I don't hear of. I'm sure there are particular psychiatric problems with cardiology. I think they don't see any need for anything except the medical. They're so geared up to drama - to intensive care and emergencies, they haven't an interest in the more human side. And they have to some extent, to ignore it in order to cope and to be able to go on working there.'

The social worker said,

'Their science training tells them that you can't let emotion get in the way if you want to think logically and rationally. So they risk forgetting the human element and thinking that feelings are not valid. But if you irrationally try to deny pain and anxiety they can disturb you more than if you acknowledge them.'

Compared with many papers on the psychological effects of cancer, there is little published work about the psychology of congenital heart disease, such as fear of mutilation, or the symbolic importance of the heart which is, as one mother said, 'the centre of the body'. Doctors have been described as gatekeepers to

resources. Contact between patients and paramedical workers often depends on doctors opening gates by referring their patients and also by giving and receiving knowledge, and by taking more than medical insight into account. If gates remain closed, for example, if patients are not referred, if social workers are expected to support medical decisions which they do not reasonably understand, and if doctors exclude nonmedical considerations, then the assumption that cardiac patients need only medical care can become a self-fulfilling prophecy. The social worker said, 'If doctors keep ignoring psycho-social information from the nurses, the nurses can't value it and keep passing it on, so decisions can't be made with the full facts.' Psycho-social needs may then pass little noticed on an individual level and on related general levels of medical practice, research, publications and training. As Weber pointed out, rationality does not inhere in things, it is attributed to them. We only value things if we notice and understand them.

A further reason, for avoiding nonmedical issues was doctors' wish not to intrude unnecessarily. This was mentioned by an SHO when talking of a family she was worried about with the social worker in an office at HH.

SHO: I don't want to be nosey and interfere. I wouldn't want people prying into my private life. But I feel we've put this family under such pressure. They are strange, but they might have gone jogging happily along if we hadn't interfered. But we've kept their child in here for so long. And there's the suspense of not being able to tell them what was wrong and what we could do. The GP says the father has threatened to kill Alan. [] I feel responsible and that I ought to do something, as long as I can help, not just interfere.

SW: I think Alan is a very upset child and we are not doing our job if we send him home in a worse state. The mothers complain that the children get so bored and depressed here. They're left on their beds and they're lonely. They need a teacher and a play therapist. At least we ought to initiate some family therapy which they can follow up at home, though it will take a very long time.[] Here, children bring in problems and take them home again. That whole aspect is totally missed. We need short term support here, to help to prevent long term problems. And to make the other staff, doctors and nurses - to raise their consciousness about children's warped fantasies. []

SHO: At my last job we reluctantly sent a child back to a violent home [] and a few weeks later he was dead. I felt responsible then, and I feel very anxious about Alan.

The SHO's words illustrate doctors' wish to select only that information which they can use for effective, beneficial intervention.

Sometimes I felt so worried about a family, it was difficult, say on a ward round, to think about other patients. In order to be able to divide their attention fairly, doctors had to stand back from becoming too involved. One method of sustaining this necessary discipline was to use a medical language which translated a patient's suffering into impersonal, manageable terms. The following example shows the power of words to create different responses, and the way in which the social worker tried to bridge the language barrier between the medical and the parental response. The social worker heard a medical report that a child was very ill, given in rather formal terms about cardiac function, which did not enable her to realise what the child and parents were experiencing. Later when I saw her she looked white and was shaking. She told me:

'I've just met Mrs Davis. She came into my room and burst into such terrible sobs. They just want to go home. She knows her daughter is dying, that she is very, very ill. It's awful. If she were my child I would opt for surgery. I couldn't bear to go on with this. It's so dreadful to see. I hadn't gathered this from the doctors.'

In this case, the social worker interpreted her part in the consent process as reporting (in Bion's terms 1962) the family's 'direct, raw,' subjective experience, and their wish to go home, to the doctors who were considering surgery. Parents used the social worker as their advocate. One mother told me that she was angry about what she saw as unnecessary treatment, but she wanted to preserve good relations with the doctors. She said:

'I told the social worker exactly how furious I was and think she has had a word with them. Things are certainly better.'

Link workers who interpret for Asian mothers at the London Hospital found that they inevitably became advocates; explaining to the staff how routines distressed their patients and working for improvements in care, while also explaining to the mothers reasons for necessary practices. In a similar way psycho-social

workers act as interpreters and advocates between the medical and the family world. Sometimes doctors assume that interpretation need be only one way: to explain medical advice to the family. Psycho-social workers saw their work as two way and thought a vital part was to help doctors to listen to patients. They were concerned if doctors seemed not to listen. One said:

'Information gets lost. It's told to people but it's not passed on. No one puts it all together, so decisions can't be made with the full facts in mind. Some doctors are very formal, they inhibit things. They are full of things to tell and they won't listen - or only to information they decide to ask for, strictly in the given way they determine.'

Yet social workers also appreciated that people's accounts could be complex and many layered. One said:

'It's all splitting and projection. For example, we put good things into doctors, and think they are kind and powerful and then parents get angry because doctors aren't omnipotent. But how much should we reasonably expect from them?'

When consultants held a joint session with a family, the social worker found this very beneficial. She told me of an interview with Alan's father (see above) one evening.

'Alan's father was very cool, not at all vicious and explosive as he had been with me earlier. He started by saying why couldn't Alan have a brain scan if we didn't know what was wrong with him. Dr S laid it all out superbly, precisely, in beautiful clear language. He described exactly what was wrong and what could be done, and how there is only one other hospital in the world where this could be diagnosed and treated. He spoke with great authority but he was very calm and relaxed. He wasn't authoritarian, but Mr H had no way of manipulating him. Dr S made it clear precisely where we stood with treatment, and we all felt calmer and more confident.'

A few ways in which connections between medical and psycho-social issues are managed have been outlined. Connections and barriers are created through interactions set within influential hospital routines and policies. Nonmedical staff can play an important part in the achievement of informed and voluntary consent in helping to draw attention to underlying issues and to elucidate

people's differing responses. This often complicated process helps to reconcile parents' hopes and fears with the final medical decisions so that parents feel that they can consent reasonably freely and willingly. In some cases, psycho-social workers help parents to understand medical decisions more clearly, and sometimes to influence and alter medical decisions about surgery.

Operation routines

In giving proxy consent, parents agree to delegate responsibility to the hospital staff. Yet it is not always clear where parental responsibility stops before surgery or resumes afterwards. If parents are not happy about their child's treatment they have to decide whether they have any right or competence to try to intervene. Each hospital shared similar routines, but differed, for example, in that CH had far more surgeons and typed theatre lists were circulated well in advance. Many children had to wait in CH for four days after admission before surgery. I was told that the blood bank needed this time to arrange blood supplies for theatre.

Waiting for surgery

At HH, theatre time was limited. Surgeons planning the lists juggled with the likely length of the operation, its urgency, the problems of cancellation. For example, it was easier to send a UK patient, than a patient from abroad, home to wait for postponed surgery. Operating lists were routinely overbooked in case, say, a patient developed an infection which meant that surgery would have to be postponed, or if, after a difficult case, there might be time for another long case or only for a short one. Surgeons told me that if they could select almost at the last minute from a variety of waiting cases, the theatre time could be used most effectively, ultimately to the benefit of all the waiting children.

Last minute selection could create problems. If parents had to make complicated and expensive arrangements, or had to put their other children in council care, they felt under worse stress when operations were delayed or cancelled. Mothers on

supplementary benefit had to bring their SB book into hospital to claim the fares but could not draw more than two weeks of payments away from their home post office. One father missed two weeks of contract work in Ireland and paid for two return flights while waiting for his child's repeatedly deferred operation. Unemployed and forces families received financial help but low paid families had little or no help with the daily mounting costs of transport, telephoning (often through neighbours), paying for the care of their other children, and for their own meals and accommodation. Children with chronic illness tend to be in below average income households because parents' careers are disrupted. (Burton 1975)

At a time when parents most wanted to act responsibly to resolve problems, many felt at their most weak and vulnerable. There is not space here to repeat the parents' words of sadness, frustration and anger at being trapped into routines which they thought were partly unnecessary. Informed consent to surgery involves relinquishing autonomy and control over time, resources and routines which deeply affect the whole family in many ways seldom recognised by hospital authorities. Utilitarian and scientific principles of efficiency separated public work and private family areas of life, instead of recognising that this disconnection was at the root of many family difficulties.

Consent and the trust that consent entails are assumed to relate to benign authority, implying that parents are asked only to consent to procedures which will benefit the child. If they perceive that they have consented to a complicated process involving benefits and harms, parents are faced with several dilemmas. Needing to trust in medical beneficence on which their child's life depends, parents are reluctant to recognise that harms might be involved. When they begin to have doubts, they are uncertain whether their doubts are valid. They do not know whether or how to express criticisms on their child's behalf, as in the following interview. The mother quoted next wants to trust in the good intentions and the efficiency of the staff. 'She knows that delays are complicated by medical considerations which she does not fully understand and that therefore she cannot judge the whole situation. Instead of

talking as if she could discuss her view on equal terms with the staff, she spoke to me in the language of uncertainty and helpless dependence, of her 'despair'.

Mother: I don't think we've been treated badly at all, but we came in nine days ago on Sunday expecting the shunt. Then they said they were toying with the idea of doing a catheter on Wednesday. That didn't materialise. Then it was going to be Friday but some emergencies came in. So on Thursday evening they said it would be next Tuesday. I've seen people come in and go to theatre and we're still sitting here.

I feel we've been put off because it's just a shunt. I don't know whether a shunt is vital. Well I know it's vital to Nigel and it's vital to me for Nigel, but compared to what the others have done, is it important? I don't know. They seem to keep saying to us "Tuesday, hopefully," "Friday hopefully". I know he isn't desperately ill and urgent, but I mean how long can you go on a "hopefully"? I get terrifically geared up for it each time, and then to let the tension go again, to be repeated the next day, which - I'm, - I'm finding very difficult. It makes you wonder, how much do they care about him? They are very understanding. The sister, I asked her, "Am I being unreasonable?" She said, "No, you're not.

PA: Unreasonable?

Mother: Well, because I was in despair when they were going to cancel again. They said the only hope was if this little boy had a temperature and the worst of all was he was a private patient. I asked if he was going first because of that. They just shrugged their shoulders. It makes you very bitter.

When babies had to be starved, sometimes for many hours before or after procedures, they and their parents became extremely distressed, as did some nurses. One nurse said:

'It's all right for the doctors. They just say, "starve for eight hours". We have to do it.'

The junior doctors intervened when the baby's health might be affected and they also were aware of the stress on families. One SHO said to another,

'I've put Richard on a drip. His blood sugar is getting too low. His parents have been so mucked about. Last week they were told it would be Friday, then this Tuesday. This week they were told it would be next Friday, then suddenly they were told it would be today. It can't be helped he's been waiting so long. Mary's been in theatre for hours now, I expect they took about two hours down there trying to get a line in.'

Getting the line in meant inserting a tube into a vein or artery partly for administering anaesthesia. This could take from ten minutes upwards, and was just one of the procedures which prevented surgeons from predicting how long an operation would take.

The rituals before surgery made some parents feel at a distance from their child. A mother who was sitting beside the cot in which her child had been screaming for a long time, said to me, 'I don't think I'm supposed to pick him up, because he's all clean ready for theatre.' Although she felt unable to help the baby, she also felt unable to leave him for what might be their last time together.

Children had to wear white gowns, which many of them hated. Some hospitals now provide patterned gowns or let children wear their own clothes as long as these can be easily removed. During a ward round an SHO said of one baby who was wearing a long white gown, 'The family has a history of SIDS [cot death].' The mother said to me:

Mother: She's going for a burial.

PA: For what?

Mother: A burial.

PA: Is it a barium?

Mother: Oh yes. I wonder what made me say that. Oh if only I could stop her crying. She hasn't been fed for five hours. What will a barium be like?

When children were old enough to ask questions about delays, parents tried to hide their anxiety and to reassure the child, which was difficult when they did not know what would happen and so what to prepare the child for. Parents' relations to children mirrored their relation to the staff; many parents depended on being given medical and nursing information in order to be able to translate this into terms which would inform and reassure the child.

HH ward patients were divided mainly into three large rooms for babies, under fives, and school age children. Parents with babies could feel isolated because the cots were partly screened from one another. Mothers said, 'You feel you shouldn't go too near other people, everyone is so worried about germs with the babies.' The school age room was next to the playroom. Children

brought in activities, some made friends and their parents could usually explain to them, prepare and reassure them. Their main difficulties were loneliness and boredom, and vivid, imaginative fear about the treatment. Adolescents could be extremely afraid of surgery. One fifteen year old was frightened if her mother even left the room. Her operation had to be cancelled after she had been taken down to the theatre and she had to go through this alarming stage twice. Whereas small children recovered quickly, some even shooting down the slide on their tummy a few days after surgery, older ones moved slowly with obvious fear of pain for days after surgery.

The stage which seemed to be most difficult was in the under fives room. Parents could usually explain little to the child, who would demand almost constant attention, struggling to get down on to the floor, the normal play place at that age but the room was too crowded. Hard upright chairs were impossible for nursing a child comfortably, so bored children spent much time on their beds. The play room had no comfortable area for small children and was at the other end of the ward. Afraid of missing events such as a doctor's visit, parents sat by the cot or just outside in the corridor, continually moving the child out of the traffic. The room was often noisy with crying, talking, shouting, and the horrible sound of children being 'sucked out' by physiotherapists. My interview tapes from that room had so much background noise that they illustrated the problems of trying to concentrate on informed discussions about surgery. If children did fall asleep, they often had to be woken by one of the staff. 'If only they would post up a timetable of the rounds and the ward routine,' said one mother, so that we knew what to expect next and then we could plan their meals and their naps.'

Consent and care

These details are mentioned in order to indicate many ways in which parents felt helpless. In consenting to surgery, they had also consented to some circumstances which they disagreed with and which increased their difficulties. From the medical or philosophical view these details may seem irrelevant to informed consent. From the parents' view they were crucially important

because giving proxy consent is about care. Implicitly it prompts parents to ask: What is the best decision to agree to for my child's medical care? How can I care for my child in order to help him or her through surgery in the best way? What sort of care is provided by the hospital staff to whom I have entrusted my child's wellbeing? Was I right to agree to this? Where does my responsibility end and that of the staff begin?

How are parents cared for in order to enable them to care for their children? Hoxter's theory (1977:214) that 'the mother has to cope with these feelings of alarm and distress in *herself*, before she is able to respond appropriately and give relief to the baby' is relevant here. The following example indicates the kind of experience which could happen in the under fives room. One mother told me that her 18 month old son was waiting for an operation.

'They've got to patch up two holes and a couple of valves have got to be enlarged I think. They've cancelled the operation twice and I want to get home. My two other boys are rather clingy. We're not on the phone so I send them postcards. My boyfriend's looking after them. I didn't want them put into care. I'll have to draw some more benefit soon because he hasn't got any money or a job. I don't know what I'll do if we have to stay longer than two weeks. My landlord said he wouldn't notice my friend staying there, in case they stop my benefit. []

Seeing them laying there asleep. They look so innocent and comfortable. You feel funny inside. The longer you wait, the harder it seems to be. All you can do is sit and hold his hand. You never know what's going to happen next.'

Stephen awoke hungry and irritable and having to be starved for the operation which was later cancelled again. With nothing to do he wriggled and worried his mother and then bit her. Already extremely fraught, she bit him back 'to teach you that hurts' and he began to scream.

That evening she was walking around with him because, having been asleep after the premed for much of the day, he was now waking up. She said that he screamed if left and she would have to miss supper. She seemed to be feeling exhausted, lost and unable to find help. I offered to look after Stephen and enjoyed holding the warm little boy. Next day, Stephen died during his operation. His mother's memories of their last days together were not likely to ease her grief. About one in ten of the

surgery patients died in the unit. Consenting to high risk surgery for their child is arguably one of the most difficult times parents can experience, and much of the strain comes from trying to appear calm in order to reassure the child, yet feeling helpless.

'Your whole body is pumping adrenalin around - ready for action to protect your child - and there is nothing to do. You feel so helpless. Yet anything you can do is precious to you, to help you to calm down and stop feeling so useless.'

said one father. Parents needed the support of friendly staff and clear plans, but some felt isolated and many felt uncertain.

Taking leave

An important moment for families was just before the child was taken to theatre. There was often a rather uneasy transition from the parents' careful attention, to institutional routines. For example, the parents of a six year old told me very quietly so as not to wake her 'it's only a 5% chance of her making it'. She was asleep when the trolley arrived.

Nurse: You won't get any porters, there's a union meeting I'm afraid.'

Mother: Can we come with her?

Nurse: Oh well, you can come to the lift but there's no point really because she's asleep.

The mother kissed the girl and asked the father if he wanted to say goodbye, but there were too many people round the bed. She walked a few steps and then suddenly walked another way crying. The bed crashed against the doors and this woke the child who stared around her.

Taking leave was just one of the events for which parents wanted to be informed and prepared to know what to do. Many mothers said that afterwards they felt angry or regretful that they had not known how to manage better what was to them a very important occasion. One mother, who had been a theatre sister, wanted to stay until her twenty month old child was unconscious.

'Basically it's not done here and different people came with reasons why I shouldn't go [to the anaesthetic room]. They said the gases might induce labour because I'm pregnant, and there is no privacy, I would be able to see into the

theatre, and that I shouldn't go into the sterile area. I just stayed with her. She was not upset and she was conscious although they had told me she would be asleep. The consultant anaesthetist came out and said I could go in so I just changed into some overalls and I could actually hold her while she went to sleep. He was very good but I felt the nurses were pretty hostile. I held her till he put the mask on. She cried but, um, I felt it was a lot less traumatic for her. And I felt a lot better about it, because even if it is only a short wait there, they see so many faces come and go and their perceptions are altered by the drug they've had. So I felt it was just not done to leave her.

I felt better while she was in theatre. I knew I had done everything I could to reduce her fears and I think in the end she will have suffered less trauma when she comes out of here. The child needs someone familiar until they are asleep and they haven't time to get to know the ward nurses, anyway I don't think the nurses stay down there long enough. I think some mothers don't realise that the child may have to wait a long time and anyway can get really scared and frightened down there. It is very important to get the child to sleep as peacefully as possible and only someone they know and trust can do that. If I hadn't been able to go I would have felt very angry with the system and that would undermine my confidence.'

This was an example of a stage when many parents felt very strongly either, with this mother, that their care was important, or else that it was wholly a medical matter. As my survey of parents' views shows (attached p15) most parents wanted to stay with their child for longer than they were usually encouraged to.

Doubt about medical delay

An added anxiety for some parents was doubt when there was delay whether this might harm the child. There seemed to be a tendency to delay some higher risk operations. A consultant said, 'When there is pressure on theatre time it makes sense to put off the highest risk surgery.' Some parents then felt under pressure to request an end to delay. An example is the mother who told me:

'They say all her blood is going round the wrong way and it's been roughing up all her tubes for four months. They don't know how much damage it's done, but it gets worse, and eventually, um, - they, er, without the operation she'd have a matter of weeks. She's got a one in six chance of surviving the operation - but she's got to have it. He [consultant] said - um - "I can't give you, not an exact success rate because we've never done it on such a small baby." They don't know how she'll be later on, - because

basically it's all down to how much damage they find wrong with her when they open her up, how long she's got to live.'

The parents understood that the operation was urgent in order to prevent further deterioration, and so to improve the baby's short and long term chances of survival. They also felt some urgency in wanting to know the effects of surgery. The operation was postponed and when I saw them a week later they had been waiting for two hours after the time their child was due to go to theatre and were worried that this might mean another cancellation. They told me that they were uncertain whether they ought to 'make a fuss' on their daughter's behalf. They felt torn between 'being a nuisance', or being inadequate representatives of their child's interests. They asked the sister when the baby would go down and she replied she did not know, went into her office and talked about parents 'pestering' her.

Nurses and consent

The HH ward sister was in a difficult position, in between stressful hospital routines which she had to administer but could seldom influence, and the families' distressed response. She told me that her job was 'just endless hassle', administrative rather than nursing, and she seldom had time to sit and talk with families. She was continually being asked to find more bedspace, transport, nurses and time than were actually available, and in order to defend herself from the disappointment or anger of parents and staff about the inadequate resources, she tended to be abrupt and distant and to stay in her office. Families and nurses missed having someone to turn to in their distress. Nurses could become very unhappy about the effects on families of the heart conditions and treatment and hospital routines. Unable to alter most of these circumstances, many nurses wanted at least to sympathise and to support families. They were frustrated by the impersonal nursing routines which put barriers between nurses and families. For instance nonintensive care nurses told me:

'The children get terribly bored and difficult to handle. They need a teacher here. I set up a game of table football but as soon as we started I was sent to clean cupboards for three hours.'

'Some nurses think you're skiving if you sit down and

talk with patients, they make you go and clean the sluice.'

'You never have time to get to know families, you feel cut off from them, because you're always being moved to other patients. But it is nice if you can have a few days in one room. Then the parents really start to talk to you, not just as if you're a nurse, but as if you're their friend.'

Nurses can influence the quality of patient consent in their response as channels of, or as barriers to, communication. Besides translating medical information into clear terms and helping to unravel misunderstandings, junior nurses especially, being lower in the hospital hierarchy, can be aware of patients' anxiety and criticism. Yet if junior nurses are not encouraged to report problems to seniors who help to resolve them, then they are liable to share patients' sense of anxiety and helplessness. One way to deal with this burden is to avoid talking with patients. It seems that at many levels communication can be encouraged or discouraged. Open discussion between different grades and professions in the hospital is likely to encourage freer discussion between staff and patients.

Nurses were strongly aware of the disconnection between medical and social considerations and the distress caused to families. They were critical of the operating list management. Typical remarks were:

'The surgeons have paramount power to cancel operations without regard for the distress it causes. It's so illogical and wrong. No one is in control of this unit. I can't approach them and feel they'll listen. I'd have to overcome their opposition. No one can influence them.'

'No one can stop the surgeons' idiosyncratic decisions. But is it reasonable to allow them to do this? Why are we so afraid to challenge them?'

A sister told me about a mother whose first baby had died of an almost always fatal heart condition. Her second baby was now in the unit with the same defect.

'She really loves that baby. It's as if she's in a world of her own. If only we could have a whole unit meeting devoted to how awful it is for parents - this cancellation. We should have thought far more carefully about what it all means. She stayed up all Wednesday night cuddling him. Then the operation was cancelled. If only the dreadful

effects on parents were taken into account. She had to wait over the whole weekend.'

The consent form

To the parents the form was a crucial symbol of their responsibility for surgical decisions. Signing the form made some of them conscious of guilt, of 'signing a death warrant'. Mothers often preferred fathers to sign. Yet it was seen by some parents as a moment of relative power, when they could at least delay consent until they were satisfied by medical answers, and when they might get evasive doctors to answer their questions. On the other hand to doctors, signing the form was a routine, often in HH left to a surgical SHO, who might know very little about cardiac surgery, to do in the evening when senior doctors were not easily available. Some consultants felt the form was unnecessary and entering the hospital should be interpreted as tacit consent for everything which doctors decided to do. (Although they also said parents often could not be informed until final tests had been done after admission.) Those who trusted medical beneficence and wisdom saw little need for a consent form. A nurse said, 'To the doctors the consent form is just a piece of paper, like signing for the carpark.' The form as a legal document was worthless in itself, because no court would be satisfied that the form was evidence that consent was informed, and yet it was an essential part of legal evidence which would have to be produced in court. So legally, signing the form was an empty formality, unless it was preceded by reasonable discussion. The purpose of describing the following examples of formal or assumed consent is not to consider whether they are representative, but to show how they illustrate certain underlying practices and assumptions. Judging from the comments of many staff these examples from HH were not exceptional.

Observations of formal consent

It was not easy to observe the signing of consent forms. I was uncertain whether frequently changing surgical staff and, especially, parents would want me to watch an event which parents thought was so important. The timing was uncertain. Doctors tended to arrive with the form at any time, it was difficult to

be around at the right moment, as many parents found. Frequently, one parent would be absent while the other signed the form, and they often found that the busy doctor hurried away before there was time for the discussion they had hoped for. In this example, a surgical SHO said he would probably get consent during the afternoon but arrived at 7.30pm. We went into the toddlers' room where the mother was sitting on the father's knee which looked rather childish for an event which they had earlier said they thought was very serious. However there were no spare chairs in the room.

The consent form states that the doctor who also signs the form has explained 'the nature, purpose and effect' of the operation. The surgical SHO, in only his second week of cardiac surgery did not seem to consider himself responsible for explaining the nature of the operation, correction of atrioventricular septal defect* in a six month baby. He assured the parents several times that paediatric cardiology was very complex and their child's cardiologist and surgeon were among the very few people in the world to understand it thoroughly. He showed the parents the form in the darkened room, and left them to sign it, returning later to collect it. Earlier he had informed me that it was crucial that parents did not lose their faith in surgery and that sociologists were a dangerous influence, creating mistrust. He seemed to assume that parents needed reassurance about the excellence of the unit and that information would merely arouse anxiety. However, he was in a very difficult position, being reluctant to admit his ignorance because this might undermine the parents' and his own confidence.

When the surgical senior registrar agreed that I might observe his next consent-signing, this was for a baby with transposition of the great arteries.* Over the two years of my study, longer term problems were becoming apparent in older children who had had Mustard's and Senning's operations for this defect. Doctors were cautiously coming to prefer the new switch operation* in carefully selected cases. Although the switch had a higher early mortality, it was hoped longer term results would be better. Children were referred from other cardiac units because of the growing success in this unit.

In other words, both consent forms were concerned with controversial surgery against a background of medical uncertainty and choice. With the atrioventricular septal defect there was the debate about whether first to prepare with a banding* or to proceed immediately to correction, and if so how early. In the second case the parents had been persuaded that it was worth bringing their child from Portugal in case he could have the newer switch operation. The medical meeting had decided that morning that the baby had extra complications and therefore should not have a switch.

We stood in the corridor next to workmen using loud electric drills with people walking past the ladders and a nurse trying to manoeuvre a weighing machine around us.

SR: Well, you know his arteries are the wrong way round?

M: Yes.

SR: And the blue blood goes - and the red blood goes - [waving his hands]. By putting a joint up here [waves] that is what we are going to do, Okay? So if you'll sign this form. My name is Mr ____.

E: [Murmurs to his wife.]

M: Is it a Mustard's?

SR: Yes.

M: Not a Senning?

SR: No - well there's no difference between the two really.

M: [Talks with the father.] He can't have a switch?

SR: Well no, the left side is too ...

M: And he would have to have had it earlier?

SR: Yes.

M: The surgeon said the risk was higher.

SR: Yes

[By looks and murmurs the parents convey a sense of the Switch being their preferred solution although regrettably not possible, and they sign the form.]

This example is given to show that the surgeons' faith in benefits of their work could lead them to behave as if signing the form was an empty and unnecessary formality, and not the best use of their time. Both doctors knew that I was studying informed consent and so presumably considered that their methods were appropriate.

A minor procedure

After the Portuguese parents had signed the form, the senior registrar then went to see a baby who had a recurring blister on

the surgery wound, and he said, 'We'll just open it up then it'll have a chance to heal up from underneath.' A nurse brought some forceps. The baby, who was asleep at first, bled onto his father's knee and the nurse kept being sent for more packs of dressings. The baby woke and cried quietly and rather hopelessly, and afterwards stared around with a very scared, wide-eyed look, which I saw in a few long-stay babies. When the surgeon had gone, the father kept saying "Sorry, sorry," to the baby, as if distressed that, from the baby's view, he was so closely involved, almost identified, with the painful procedure, and that he was unable to offer any protection or security, even when the child was asleep in his arms. He said, "Good thing my wife isn't here - she would have given them a piece of her mind," sounding angry and shaken that this had been done without warning. Lack of explanation prevented the father from being able to prepare the child or to intervene on his behalf, for example to wake the baby first, to agree on a suitable place, to ask for analgesia. The nurses were angrily critical that the wound was opened several times without any analgesia, and that their views about necessary pain relief were ignored by the surgeon.

Legally, formal signed consent is required only for invasive procedures, such as surgery and catheterisation, and not for procedures classed as minor or noninvasive such as injections or echocardiography. For these latter, assumed consent such as the patient lifting an arm for an injection is legally considered sufficient for adults, while children's protests are usually ignored and their parents' presence or absence are equally interpreted as agreement to staff decisions. Hospitals do not share the *in loco parentis* status of schools, and even that status does not permit teachers to consent to medical procedures on their pupils. It is probably advisable to ask parents' permission before doing procedures likely to disturb the child, since touching the child legally constitutes assault. Discussion beforehand, although holding up busy doctors, also slows medical interventions to a pace which gives families time to adjust and to reduce the child's fear of sudden, unexpected pain.

Consent and echocardiography

From the medical view, echocardiography* is a safe, noninvasive, comparatively quick and easy method of obtaining information. A few minutes in the outpatient clinic can now produce information which formerly might only be obtained by admitting the child for catheterisation or surgery. Possibly because echoes are so much easier and safer than other methods, doctors tended to dismiss some patients' reservations, that echoes were mysterious and alarming high technology incurring discomfort, anxiety and without proven lack of risk.

Some doctors carefully prepared children and parents, using the echo time to talk with them, to explain the images, and to help the child to lie still and relax. Others worked in silence or spoke only to their colleagues, leaving the family in mounting suspense. Knowing that the transducer does not hurt like a needle, some doctors overlooked the usefulness of reassuring children. The transducer can be pressed firmly and uncomfortably. Literature on childbirth has shown how tension and expectancy of pain can exacerbate discomfort into perceived pain. Children were expected to lie still for long periods in dark rooms and some families found the experience an ordeal when they were waiting for serious news. If the child became very upset, doctors variously responded with persuasion and distraction, force, or taking a break and trying again later. For example, an echo of a four year old was presented at a medical meeting with the humorous comment, 'One attendant at each limb pinning him down because he was a bit wiggly.'

A further medical advantage of echoes was, as one consultant said, 'We can leave fellows to do as many echoes as they like, it's a noninvasive procedure.' Fellows were doctors, usually from abroad, studying cardiology. The senior registrar was aware of problems for the families. He would tell the fellows not to do unnecessary practice echoes, or take babies to the echo room where they became too cold, not to take children without informing or asking parents, not to leave parents with the impression that another echo meant that a new problem had been found. He wanted them to be careful to explain to parents 'that echoes had no dangers or side effects'. The ward sister was

worried when children she was nominally responsible for were taken from the ward without her knowledge or the parents'. Besides the constantly changing medical team, many doctors visited from the Institute attached to the hospital and seemed to assume that they should have open access to the children and to their notes. Clinical examination was very important in cardiac training. An adults' cardiologist asked if a group of visiting fellows could intensively observe the children's unit for three weeks, 'They've been complaining that they don't see enough patients. I told them to wait until they came here. They want as much hands on stuff as possible. I know it will interfere with your work but ...' In postgraduate teaching hospitals patients were expected to act as teaching aids and little attention was paid to possible disturbance to them. Often, when I sat down by a cot to talk to the parents, the child would make a tense movement as if expecting some discomfort. Those old enough to understand relaxed when I said that I was not going to touch them. Doctors did not wear white coats. The children had no way of distinguishing people who might suddenly do something painful to them, and many children seemed to live in constant, tense expectation.

During nurse support meetings nurses criticised what they saw as an imbalance of harm and benefit during some echoes.

'They did an echo in the morning and told the father the baby was dying, there was nothing they could do, it was hopeless. He was sitting there crying his eyes out. You only had to look at his face to see grief written all over it. And they came and did another echo for a whole 90 minutes. They wanted a tape of the rare condition. From the father's view, he hadn't seen this before, they might have been hurting the baby. They really dug the probe into her stomach. She was blue and breathless and very exhausted and he must have been thinking they were making her even more exhausted. [] He wasn't allowed to hold her until they had finished. Three of us kept saying, "Can't you be a bit faster?" They said "We'll only be two more minutes," but they were half an hour.'

'The father knew it wouldn't do any good or help his baby. It must have seemed to him like an attack on her, just using her as a teaching aid, an object. Five or six doctors came along and took turns, they were joking and laughing, while the father wept.'

'Those echocardiographers don't take much notice of us. They treat us as dirt. I wanted to take the plug out of their machine, or smash it up with a hammer. They couldn't see for themselves so they wouldn't listen to us saying how

upsetting it must be. They were talking about how rare some of the different parts were. All they care about is their machines.'

This example shows how technical medicine can divert medical attention away from the patient as a person and can conflict with care for the family. When doctors have to ask for formal consent they are reminded that patients have a right to control the amount of medical intervention. Children are often most frightened and protesting about procedures which doctors call minor and noninvasive but which can invade patients' privacy, dignity and security. These can cause painful anxiety and tension, as much if not more than invasive procedures requiring formal consent, which are generally performed on unconscious patients. From the families' view, salient issues are not physical invasion, thermometers represent this, but the anxiety and distress caused by procedures and also whether they directly benefit the child or use the child for other ends.

Two days after the meeting just quoted, a four year old from Malaysia arrived with his father who spoke no English, and with two interpreters. The boy seemed terrified while his father wiped away his tears. The men looked worried about his frantic breathing. The consultant examined him gently, and said, 'He's frightened, that's why he's breathing like this. We'd like him calmer'. He explained the operation, and the interpreters then asked if they need stay. The consultant said, 'There's no need medically if we can get all the tests done.' The interpreters said they would return later to take the father to his hotel as private patients' parents could not stay in the hospital. Next day they would meet the surgeon to arrange signing the consent. No one seemed to see any advantage in explaining the tests, the ward and hospital routine to the boy or his father, or in interpreting the child's needs to the staff. They did not seem to connect talking to the child with calming him, or to regard explanation as a therapeutic part of the procedures. The SHO said he would 'do the bloods then the echo' an order which would be likely to make the child more frightened and difficult to calm.

General rules, such as that certain procedures do not require

formal consent, can obscure the advantages of explanation as a part of each step in investigation and treatment. Separating talk and action, information and intervention can increase distances between doctor and patient, if doctors are trained to look at data on machines instead of sensitively picking up cues from patients as the nurses do and as the consultant linked breathing and anxiety. Informing inpatients about procedures tends to be left to junior staff. When they do not have time, knowledge, help and an example set by senior doctors, juniors may protect themselves by being evasive. In so doing they are reinforcing inequalities between staff and families in knowledge, status and freedom of choice.

In this chapter, I have suggested that physical and mental access for parents, (being acknowledged, welcomed and respected), and professionals' attitudes (of either supporting or of distancing parents, raising or lowering their status), can be important influences on parents' ability to give informed and voluntary consent. Nonmedical staff can have a crucial influence on parents' ability to be present at, to understand, share in, and cope with, discussions about treatment. I have also suggested that surgery involves a set of practices, some of which could be altered to avoid distress and to enable parents to have more say in helping to prevent harm to their child. The following chapter considers problems of consent and consensus experienced among the cardiac team.

CHAPTER EIGHT

THE INPATIENT CONTEXT 2. THE CARDIAC TEAM

'There are indeed crucial conflicts in which different virtues appear as making rival and incompatible claims upon us. But our situation is tragic in that we have to recognise the authority of both claims. There is an objective moral order, but our perceptions of it are such that we cannot bring rival moral truths into complete harmony with each other and yet [] to choose does not exempt me from the authority of the claim which I choose to go against.'
(MacIntyre 1988: 143)

Research and commentary about informed consent tend to assume that, if problems are made clear enough, they can be resolved through greater efficiency or through a clearer order of a hierarchy of values. This chapter is concerned with inevitable conflicts in highly technical medical care of very sick children, for example: medical efficiency and progress versus the child's personal needs; fighting to defeat death versus accepting inevitable mortality; realism versus hope. Each competing value holds essential advantages and also disadvantages. They are antagonistic yet complementary. Choosing, say, medical teamwork increases the skill and knowledge available for each patient, and offers doctors a manageable share of responsibility. Yet it can entail making care, and the consent process, impersonal, fragmented and confused, when many teams (medical, surgical, anaesthetic, nursing, paramedical) are responsible for patients.

By showing competing claims inherent in informed consent, I intend to suggest that instead of assuming that there are always clear moral choices, we need to attend to ways of coping with medical, moral and social uncertainty. This chapter reviews the difficulties of keeping the whole cardiac team, as well as the families, informed and united when there is uncertainty about the means and ends of medical choices. Since the work was shared differently in each hospital, to avoid confusion in this chapter examples are taken only from HH, although the arguments generally apply to both hospitals. Some examples are not specifically about consent to surgery. They are intended to illustrate the general quality of discussion between staff and parents, either when surgery was one possible option, or if there were attempts

to agree that treatment had failed and that parents should be asked to consent to ending treatment.

Team work

The team work in HH was like a mosaic, but the pieces of the mosaic were not all clearly agreed. They did not tessellate, they overlapped and left gaps. People became uncertain about who had said what, when and where. The staff differed on how the work of informing parents should be divided between them. Many parents were confused by the tertiary care system and by differences between cardiologists and surgeons. They were uncertain who was 'their' consultant. They received a detailed and complicated picture but sometimes in ways which tended to confuse rather than inform. It was also difficult for parents to ensure that the whole staff team was aware of the family's views, partly because different staff needed different information. Messages changed as people retained, rejected, passed on, and gave new interpretations to various details. A few examples, which represent many other cases I observed, of how the staff shared information with families and with one another will be given. The first example shows the difficulties of managing uncertainty and achieving the delicate balance between reasonable and vain hope.

The doctors often relied on nurses to help parents to understand and to transform medical information into awareness of its meaning. This example is about Richard, mentioned in chapter 7 when his mother stayed with him through the night before his cancelled operation. An ICU sister told me:

'We didn't expect him to come back from theatre and when he did the parents were jubilant. We were so pleased, but after a day or so, it became clear that the mitral valve was regurgitating. The surgeon came round today and said he's going to die. The parents are still so happy, how can we explain it to them?'

Eleven days later Richard was still alive and his parents were still hopeful. During a ward round the doctors spoke in a subdued way.

Consultant: He looks a bad colour. All the systems are failing. He won't survive. He'll just deteriorate.

Sen Reg: [Hopefully] Well the neurological system seems [].

SHO: Is it a question that he might recover neurologically?

Cons: It's a question that we cannot be 100% certain that he will not recover.

Sister: The parents want us to do everything we possibly can, as they did last time [when Richard's brother died of the same defect].

They talk sadly about the parents having no other children and not being able to have any more. The doctors question the ethics of going on or of ending the treatment and say there is no clear answer except to an 'armchair philosopher', someone who doesn't have to face practical responsibility.

Cons: I think he'll just deteriorate.

SR: Well, maybe [].

Cons: Mm. I think we should be very, very pessimistic with the parents. You should talk to them again, and I'll talk to them, over the next day or so. I think we should not just go on and on.

SR: I don't think the parents will accept active withdrawal of treatment.

Cons: Oh no, no. [] But if he arrests? - Do we resuscitate? [Several doctors shook their heads but it was not clear whether they were giving an opinion or agreeing with a senior doctor. They moved to another patient. Richard's nurse had been called away and now came back.]

Sister: I don't quite know what they've decided. I think Dr X is more pessimistic than the others.

Ward clerk: I've got these very, very nervous parents. [i.e. Ringing the intercom to ask to be allowed back in after the round. She fetched Richard's parents and as usual they washed their hands, sat down and stared at him intently. The nurse made and recorded the observations.]

Nurse: We're clearing out the system every half hour now. We were doing it every hour but now we're doing it more to see that it is really cleared out. And apart from that he's - good.

This example illustrates the levels of uncertainty in the medical prognosis, in the advisable treatment, and whether medically and morally it was best to continue, to increase or to decrease the interventions. Opinions seemed to rest on subjective assessment of complex information, and on differing experiences. In a few other cases I saw, when eventually like Richard the child died, the consultant tended to be more cautious and the senior registrar more hopeful.

The nurses' view

If the medical decision was uncertain it was hard for nurses to convey a distinct impression, either hopeful or pessimistic. If she had heard the words, 'I think we should be very, very pessimistic,' the nurse might perhaps have slightly emphasised that having to do more 'clearing out' was a danger sign. Possibly the parents gained, or firmly clung to, an impression that more activity meant more hope and determination to win. Warning of pessimism is quite different from altering the course of treatment into terminal care when hope of recovery is definitely relinquished. While treatment continues, it may be as necessary to the staff at the bedside as to the parents to keep up hope and comfort and to say, 'He's - good.'

Nurses found delay before surgery (described in chapter 7) and delay in recovery very hard to manage because of all the uncertainty, medical, administrative and psychological. They had to achieve a kind of controlled suspense: closely aware of families' distress yet having to maintain orderly routine; knowing the distress of the family yet also being part of the institution; balancing parents' urgent need for clear detail against the medical and administrative evasive uncertainty. Modern nursing methods, such as the Nursing Process, value making clear plans. Yet much cardiac care is about managing uncertainty, which is particularly intense during the crises of waiting for surgery and recovery. Intensive care nurses, sitting one to one with a family for many hours were especially conscious of this. An HH ICU sister said to me:

Sister: It's very difficult for us to talk to them. In a terminal unit it's clear what's going to happen, you prepare patients for death and you can talk openly. But here, we are working in uncertainty and that's very hard. You can't say, "Cuddle your baby because he's going to die tomorrow," but you can't be jolly and cheerful either. We need an expert to come to tell us what to say.

Some parents are very difficult, they go through such terrible highs and such dreadful lows. They seem to live from day to day and not be able to look ahead.

The staff were conscious both of the content of information and of its form of optimism or pessimism, whether it was appropriate or not to encourage hope. During interviews, some parents had

described feeling trapped in extreme uncertainty almost as a refuge against despair or vain hope. I asked the sister about this response.

PA: Some parents say the only way they can cope is to take each day at a time. They thought that after the first operation, everything would be fine. It was such a shock when it wasn't fine, that even if they were told now that all would be well, they wouldn't dare to believe it for fear of being disappointed.

Sister: Yes, I suppose each time, they thought that would be the end, and it was only another beginning of something else. But I still feel that if we could give people a plan to stick to, that would help them to formulate their own life in the hospital.

Reasons for nurses' concern that staff and parents be informed.

Nurses often had to liaise between doctors and families. They could also be vividly aware of the impact on the families of medical decisions or nondecision. They had to manage connections between striving for cure and care. They therefore thought that it was very important that they were informed and reasonably assured that interventions were necessary. In order to be able to inform and support the family through difficult treatment, and to encourage families to remain confident, nurses needed to go through their own form of willing consent to treatment, to be encouraged to believe that they were working for the child's best interests. At times they had reservations. A senior nurse said to me, 'I wish I did not have to give some of the IV drugs, the side effects are so nasty.' Actually nursing the family perhaps made her more vividly aware of the effects of drugs than were the doctors who prescribed them.

At a unit meeting, nurses and doctors discussed a case of brain damage after cardiac surgery. Roger was recovering his sight and hearing slowly, but his voice was hoarse and the doctors wanted to be certain that there was no discernible cause which they should be treating. His throat was examined, under general anaesthesia, with a laryngoscope. Some of the staff thought the hoarseness was due to being on a ventilator for so long and a laryngoscopy would make him more sore, as well as being another difficult experience for a family which had endured many problems. Some felt that the parents regretted consenting

to minor surgery which they were not convinced was clearly necessary. The SHO wanted to persuade the nurses that Roger ought to have had the laryngoscopy.

SHO: We all discussed it, we knew it was traumatic and some of us didn't want it done, but we wanted to fully document and understand the neurological problems. We did spend time talking to his mother, she did seem to understand and I don't think she was upset.

Sen. registrar SR: We were all delighted when the results showed that it was all right.

SHO: It seemed fair enough to do it while he was here, rather than have to readmit him.

SR: But his voice was getting better so why do it?

SHO: I wasn't aware it was.

SR: The parents thought it was.

Sister: It's not just what the parents feel, it's the effect on the child.

SHO: Where we went wrong, we didn't explain to the nurses as well as to his mother, so that they could back us up.

Sister: We couldn't see why - he could breathe well.

SR: Yes, we need to think about the issue of informing nurses.

Later a sister said to me,

'I know the problem, we fragment things. The doctors say, "put in another line," the nurses say to the parents, "isn't it sad we have to put another line in." Nurses don't back up the doctors. There is a gap between them. So senior nurses were saying, "why the heck is Roger having this investigation?" It filtered down to the juniors and then the parents get worried. We should be free to disagree and tell the doctors what we honestly think, but doctors and senior nurses shouldn't say that to the parents.'

Junior nurses faced directly with supporting parents needed to be convinced that they were part of a united team serving patients' best interests. Sometimes they had doubts about the trust they were expected to sustain in the parents. Here are examples of comments they made in nurse meetings.

'I don't think the doctors are straight with parents. They'll do palliative surgery when there's no correction possible later.'

'I think parents don't understand risk. They have the wool pulled over their eyes. Dr X told these parents that Fontans had a risk of 10%. I asked one of the surgeons and he said, 95% success rate. I'm sure it's much lower, about 50% I think they operate because of scientific interest, not always because it is the best thing for the child.'

Doctors tried to stand back and assess annual records. But if two or three children died after the same kind of operation it was much harder for the nurses to take an impersonal view and they could become very pessimistic about the results.

In their own nurse support meetings, run by a senior nurse and the social worker, nurses would express negative reactions, anger and doubt, but they seemed to do this in order to be able to cope. They would go on to remind one another of positive reactions by talking about successful cases and families' definite choice to try any treatment which might save their child's life.

Issues discussed by the sister just quoted formed the key themes of the nurses' own meetings: how to cope with distress, how to prepare families for possible loss, what kinds of information and care to offer. Nurses' meetings concentrated on difficult cases. The meetings gave vivid instances of nurses' aims and experiences concerning the process of informing parents about surgery. They were also occasions for nurses to work out together a clearer understanding of what they thought had, and should have, happened. The medical and nursing meetings shared parallel contrasts between medical and nursing journals. Medical concern concentrates on disease and technical treatment detached from personal circumstances. Nursing concern concentrates on the psycho-social effects of disease and the personal nursing response; on the words, actions and feelings of the people experiencing illness and care. The nurses talked about how families could be given time and counselling to help them to come to accept a decision, rationally and emotionally, with as much voluntary commitment as possible. Doctors shared these concerns individually, when I spoke with them, but rarely discussed them at medical meetings and they rarely told the story of the human events as the nurses did of this 11 year old boy. He was discussed at a meeting about stress called by a psychiatrist.

Sister (Sr): They had got him off bypass then the next call came saying he'd just died. We were all on tenter hooks. I was in charge. Everyone came and asked, even some parents. I said, "He's still in theatre," though I knew. We are a small close unit here.

Psychiatrist: I'm impressed by your human reaction here. Some people are not sure when to be human and when to be

professional.

Nursery nurse (NN): It was too new for us. We couldn't say the actual words. It was easier to say, "He's still in theatre". We'd be more honest later. You have to consider the people you are talking to.

Sr: But I think they knew.

Social worker (SW): It's partly your shock, partly to protect yourselves.

Sr: I wasn't sure if Tim's parents knew yet. I didn't know where they were.

The nurses needed to ensure that parents understood the implications of risk, partly because nurses usually take the impact of informing the child's family and other families and staff. Even if doctors gave the actual news, when nurses had to wait for the doctor to arrive, remaining silent could be as difficult as speaking. "When you ask parents to wait in that voice, they know at once. They can tell from your face." Again nurses are forced to be aware of the language of physical and mental feelings in looks and tones and sensations of being 'on tenter hooks'.

Nurses and doctors have to respond to feelings, even if the response is one of denial and avoidance. The psychiatrist pointed to the contradictions in the caring professions between notions of humane care against notions of detached professionalism, of not allowing feelings to intrude and to cloud judgement. The context of high risk surgery illustrates the inadequacy of concepts of a professional as someone who is not 'human', in two senses. First, there is the futile attempt to detach intellectual knowledge from the feeling states which actually enable us to understand and give meaning to our knowledge of risk. Second, the avoidance of relating on human levels in sympathetic response precludes the care which is central to the identity of professions such as nursing. Yet when professionals accept that emotions are an integral part of their work, the problem remains of how to use feelings in making clear decisions and, in the words of one nurse, 'being a strong, calm support'. Here 'strong' suggests not physical or intellectual strength, but emotional strength, the positive control and use of her feelings. The nurses frequently discussed how to compromise between unfeeling detachment and being too involved, 'breaking

down', being overwhelmed by distress.

The meeting continued with a discussion about trying to prepare new nurses to be able to give bad news and of learning 'to nurse' feelings, one's own and other people's.

Nurse 1: Even if you are warned, it is worse than you expect. You feel totally insensible, it's not you at all. [] You have to nurse it and cope in your own way.

Sr 1: You can't explain. Talking is so different from going through it. You want to run sometimes. If I didn't have a break next week I'd be having a nervous breakdown. But there are more good times than bad times, thanks, goodbyes, recoveries. []

Nurse 2: But why the hell couldn't Tim have been left? I'm angry with the doctors. Have we always got to offer surgery, whatever the risk?

SHO: I can't predict statistics, chances. That doesn't mean you shouldn't try. I'm not invested with ability to know. I think Tim suffered too much but -

Sr 2: 80% risk is different from days and days of fighting in intensive care.

Sr 3: Sometimes I feel really bitter. []

SHO: He'd have died a very slow death.

Sr 2: I can't see how Tim could have lived.

Nurse 4: The surgeons said he'd improved. They wanted that chance.

Sr 3: They knew four days before that he would die.

SHO: I talked to his mother at 6am. I think she wanted a "do or die" approach.

The meeting is an example of the continuing problem of ensuring the informed and voluntary agreement of all the staff to carrying out medical decisions. With constant changes in the patients' conditions and the staff shifts it was impossible to have everyone informed and in agreement about events and decisions.

This uncertainty was more obvious in the next case which the meeting went on to discuss. Nurses were concerned that when medical decisions were unclear, the whole framework of informing and relating to families could become vague also. Darren's family went through months of uncertainty while doctors tried to defer risky surgery. If left, the VSD* might close without needing an operation. Several times Darren was sent back to his local hospital. One of his sibling's had a cleft palate and another had died. The staff talked about difficulties of sustaining trust when there was prolonged uncertainty.

SHO: It's a complicated and rare condition. The technical difficulty is we don't know if the problem is failure to thrive or the VSD. [whether Darren needs medical or surgical

treatment.] I feel a bit of smouldering discontent [in the parents].

Sister: I think his mother must be so fed up and depressed, pushed from pillar to post in this place, never a proper answer, no one seems to know. I'd be livid if I were her. She's been very good. No one else would put up with it.

SW: People say she doesn't talk.

Sr: If she did she'd get very angry. She doesn't want to upset us. She's very depressed.

The aim of discharging patients, as early as possible, back to their local hospital, was partly to help the family. Yet it could upset them, as hope rose when Darren came to London that he would be cured, and fell when he was discharged but still unwell. Nurses negotiated between the family's distress and the medical concern to make objective clinical decisions and not to be pressed into giving treatment for social reasons. Darren's mother had told me that she had lost confidence and was afraid to consent to surgery.

Sr 2: I'd worry about consenting because all along she's been told the operation carries such a high risk. If I were her, I might refuse.

Psychiatrist: She's not convinced an operation is necessary. She feels a doctor should talk to them. She feels angry and bitter. [] Before, she had great faith in medicine and went along with advice. Now she feels there are two sides to everything, she wants to know more about the ins and outs and be part of the decision making process, a developing process.

The staff went on to talk about the nurses' part in opening or blocking communication between parents and doctors.

Sr: I used to dread answering the phone in case it was Darren's mother. I had to fob her off for five weeks. [] The doctors said that it was a small hole and sent him home for a week. He came back with the operation booked, but then it was as if they'd never made that decision. Back to square one, the hole was too small. Everyday on the ward round we kept saying he's not feeding, but nothing was decided. Every round they'd give you a different answer, something to appease us, but nothing was done. I was so angry, so fed up. One day I transferred her call to the registrar and in 20 minutes Darren was in the echo room.

Psych: Why don't you put more calls through to the doctors?

Sr 2: We trust the doctors like the parents do.

N: We have to get angry and upset before we go to the doctors.

Sr: We're more tactful and kinder to the parents than

the doctors are. You see it from Darren's and his mother's point of view. They see it from the waiting list view, and they want every decision to be cut and dried.

Doctors were concerned about technical risks, nurses were concerned about the psychological risks of the family disruption and fear. Nurses were conscious of mediating between parents and doctors. Yet because of the hospital routines, hierarchies, and necessarily different concerns of doctors and parents, the nurses knew that their attempts to resolve differences between the medical and the family view points were limited, leaving nurses to contain the resulting frustration.

Nurses' wishes to reach clear agreement with families were hampered on many levels: by uncertainty and change in cardiac conditions and treatment; by complicated administration of limited resources among many patients; by parents' anxiety, lack of knowledge, and partly helpless dependence. The means of giving information were not clearly agreed and shared among the staff, as shown in the next example.

Sister: Mrs Beech just comes in and says, "Oh, is he still ventilated?" And we knew right from the operation that Kevin would be ventilated for five days at least, because he had such a terrible chest infection [and problems from previous surgery].

PA: Did you tell her he might be on for five days?

Sr: Well, I can't remember telling her, because I assumed she'd know. That is the sort of thing I think should be mentioned at consent. Like, "Your son's going to be sick for a long time after the operation. He'll probably need to be on the ventilator for a week, two weeks because he has got these problems." That's a doctor's job. I don't know what the doctors say. We often ask if we can be there. Parents will say to us, "Oh he said everything will be all right but we didn't really understand a lot of things he was saying." Now if you knew exactly what he'd been saying you might be able to reinforce it. We're not simply there to reinforce what doctors say but we could certainly simplify the language. Yet a lot of doctors do simplify their language but the lack of understanding is still apparent. Some parents just seem to blank out.

A lot of the nurses get very very upset when parents are ignorant of the child's condition. They feel the medical staff don't give them enough time and they explain everything in such high-falutin language, that parents can't possibly appreciate what they are talking about. Yet I've caught myself whizzing over something and thinking afterwards, I bet they don't understand a word because it's so much easier to explain it in your own terminology.

Apart from complications of vocabulary, and agreement on who gives information, and when, the sister mentioned other problems in informing parents.

'It is easier for nurses to talk in a unit where they don't exclude parents from the rounds because then there isn't the feeling: Should we tell them? Or, do they know this? The atmosphere is very different. You're not frightened to tell parents what's going on, if everything is done in front of parents, nothing is hidden and they are actively encouraged to be there. How can you be at ease sitting with the parents for hours when you're apprehensive of them asking, perhaps, "when's he going to come off the ventilator?" and you don't know if the parents are supposed to know.

And in this hospital, the doctors will not talk to you, the child's nurse, they'll ignore you on the round and automatically seek out the sister. The nurses aren't used to being asked during the round. If she is, she'll go red and doesn't know what to say to that big group of assembled doctors. They have no rapport and that makes life difficult, because the nurses feel the doctors don't trust them, and I think often the doctors feel the nurse at the bedside doesn't tell them enough. The parents need different levels of information from different people but it isn't being co-ordinated.'

Clarity and consensus in the way the staff worked together and informed one another may be closely associated with the quality of clearly agreed information discussed with families.

Doctors and consent

After talking with the sister, I went to ask the senior registrar what he might tell Mrs Beech before Kevin's operation about the postoperative course. The senior registrar explained to me how, in Kevin's condition, 'their pulmonary arteries can clamp down while they are on the ventilator and reduce the cardiac output considerably'. Kevin's paralysed left diaphragm 'in itself will definitely predispose to collapse of the left lower lobe [of the lung].'

This doctor spent much time talking with parents. His explanation to me of Kevin's condition and treatment, when transcribed from a taped interview, took twelve pages. This did not represent a typical explanation to parents, because there was no such thing. Explanations varied with the time, and place, the people concerned and, perhaps most of all, the number of questions parents asked. Yet this interview was typical, (from

what I observed and heard from staff and parents), in five characteristics.

First was the serious way many doctors took the explanation, assuming not only that it was possible for lay people to understand concepts in cardiology but that it was important that they did so. Secondly there was the willingness to admit medical limitations related to unwanted effects of surgery and to Kevin's very serious defects. Thirdly, this honesty was handled carefully. The doctor thought that it was vital that experienced doctors explained a 'complex or political' case carefully to parents.

'If you have to redo an operation, parents are going to wonder, did they do the right thing signing the form. I've got no doubts that obviously the surgeon did exactly the right thing.'

and it was necessary to make this clear to parents. Fourthly there was the uncertainty about who should give information. Patients, especially those of children like Kevin referred from another paediatric cardiac centre and having several operations, will have been seen by many doctors who will have given various kinds of information. The senior registrar thought that 'ideally doctors at the surgical unit should go through everything [] but we just don't have as much time to speak to parents as we should.'

SHOs and nurses told me they sometimes avoided talking with parents in case they were asked questions they could not answer, and 'said something wrong or stupid'. The senior registrar thought that practice was the only way to learn and that every doctor had their 'own bit to give'. He thought SHOs varied in how much they wanted or were able to inform parents.

'For example, with Adam, we've gone over all the problems on the ward round, we all know what the others think of him, um, there are, - are some medical uncertainties why he is not well, but - overall we know this is an extremely difficult condition to treat. Many patients don't survive whatever you do, so even from the beginning a certain amount of pessimism is realistic and a good thing to present the parents with.'

Discussion about 'the informed patient' can imply a clear picture of definite facts, either repeatedly given to patients by each doctor or else systematically shared among the staff, so that for instance physicians explain the diagnosis and surgeons describe the operation. Actual practice seemed to be very different from this. Facts often turned out to be hopes or uncertain predictions. They were conveyed through attitudes, looks, tones of voice, as much as words, through confidence or pessimism (in one's own ability as well as the patient's condition), and through how interested a doctor was in sharing information.

Informed and voluntary consent concerned both patients and staff. Doctors had much freedom of choice in the quality and quantity of what they said to patients and how they entered into the doctor-patient relationship. Their part was not routine, systematic or coerced, partly because each doctor developed a personal style of working. For this reason, as well as for the volume and complexity of changing detail in many cardiac cases, responsibility to give certain information was unlikely ever to be systematically allotted among the various staff. Entirely consistent responses could not be expected from the SHOs, since every two months a new SHO was appointed, an individual with unique experience, competence, expectations and training. Interaction between staff and parents also prevented any standardisation. Some parents would be very grateful and others very critical towards the same doctor. An approach which pleased one family could upset another.

The fifth characteristic of the interview was the typical emphasis on physiology, on causes and effects of prolonged ventilation on the body systems, from the perspective of medical management. However, the sister had spoken of parents' need to be warned about what the experience would mean to them, such as how long ventilation was likely to be needed. The senior registrar did not talk about this until much later when directly asked.

SR: The postoperative course is often difficult but still the overall mortality rate would be about 10, maybe 15%.

PA: What would you say to parents about the postoperative course?

SR: I don't think I'd point out anything in particular, um, that there's a much higher risk than any other patient

because then they'll say "Why?" and then you'd get fairly technical, talking about pulmonary crises, things like that.

PA: Would you say the number of days you might expect them to be on the ventilator?

SR: Er, - yes. Usually at least three, four or five days, er, and maybe up to seven days, and then they would be convalescent another five to seven days before they'd be ready to go home.

Information about surgery can be divided, roughly speaking, into the medical view and the patient view. Doctors concentrated on the internal working of the body. Families were mainly concerned with the surface, whatever they could see, hear, or feel consciously, and with the nature of this experience, - timing, discomfort, stages of recovery, and so on. (A third type of information, how patients and parents can cope with fear and pain to aid recovery, which is increasingly considered to be important with adult cardiac patients, was rarely mentioned in HH.)

The internal workings, many of which could be precisely described, were the major medical preoccupation and were so many and complex that it was often only possible to attend to them all by excluding other considerations. In contrast, the family's experience tended to be a vague, uncertain, unmanageable and subjective matter. To parents and nurses sitting all day by the cot, counting the hours was a main concern. Doctors visiting the child intermittently and attending to many other cases had a different order of concerns. In Kevin's case of repeated surgery, predicting timing was particularly difficult. So that, although the sister thought that doctors should warn about timing, nurses may be better able to give families this kind of information. They share the families' viewpoint more nearly than doctors do and are more likely to be aware of what families need to know.

Many parents wanted to leave clinical matters to doctors but to know what the child was likely to experience and how they could help. They wanted consent to be based on, from their view, practical as well as theoretical information. Doctors' concentration on theory, and nurses' assumption that parents had been fully informed, could mean that the practical information of most interest to parents was omitted. Divisions of care further reduced opportunities to inform families. At HH parents were only

shown ICU, which was remote from the ward, briefly the evening before the operation, which many thought was too late to help them prepare their child. (In CH, very detailed practical preparation was given to parents and children well in advance.)

When told, 'the risk is 15%', parents would ask, 'What does that mean? Is that a serious risk?' When told about a lesion, they wanted to know 'what it meant' in practical terms of the child's welfare, discomfort, recovery, and so on. Again there was the connection between physiology and personal experience which doctors tended to avoid, and parents wanted to make.

Coordinating information

At HH, the two consultants saw families mainly in clinics and the one senior registrar was the main source of information in the wards. Families were usually informed during the two day admission for the catheter and when readmitted for the operation. The senior registrar held a central position, working very closely with the families, the nurses and the medical teams, and therefore aware of the need to coordinate information and support for the families and staff. During my time at HH two doctors held the post in turn and they told me of their methods of encouraging communication. These included spending much time talking with parents on the wards or by telephone before admission. 'A lot of them do phone, this proves there is an obvious need for information,' said one senior registrar. She made time each evening to talk through every inpatient with the sisters and then go to talk with any family they were concerned about. However, she thought that such demanding work could only be continued for a few years, after which she would need a consultant post which had different responsibilities and less intensive work with patients and nurses.

Her predecessor thought that much of his work concerned 'sitting down and trying to get to grips with the situation' both with individual families and with the staff team. With difficult cases who were unlikely to live, he preferred not to rely on parents' past knowledge.

SR: We don't know what they are thinking, what they've been told before. I think they quite rightly want to hear it again, in terms of the problems there are now, an unbiased

up-to-the-minute view. [He would try to sense how prepared parents were to be pessimistic] Because you're trying to be honest with them. What's important is to know how quickly you can be that honest, because they've been led to believe it is not an optimistic outlook, so it depends on how rapidly you can turn their attention to that degree of pessimism. So if the outlook is extremely pessimistic then you can sense that it comes as no surprise to them when you start saying he's not doing well.

This doctor regarded knowledge as awareness, personally given and gradually accepted. His method offered parents the chance to question and adjust their understanding, so that information was exchanged and 'sensed' and not just given by the doctor.

In the same way the doctor thought that staff meetings were important for exchanging ideas and adjusting attitudes. He arranged a meeting for all the staff caring for a two year old child who could not be weaned off the ventilator for weeks after surgery. Some days earlier I had attended a rushed ward round at which a consultant said that if the child had a cardiac arrest she should not be resuscitated, but if she had arrhythmias or other problems these should be treated. The Indian parents were later called in and briefly told the decision as they stood by the cot. They smiled silently. Of the extra pressures on overseas families of private patients there were the enormous charges for intensive care, and the language problems. It was impossible to tell what they thought of the decision. The social worker said to me of the later staff meeting;

'The meeting was useful because it became apparent that all of us had received bits of information from the parents that went unheeded. One nurse said they would be devastated if treatment were stopped but none of us knew that. We need to meet as a team to carry responsibility. It would make decision making and anxiety less difficult.'

The senior registrar said:

SR: I've no doubt that sort of meeting should be held every week, to clear the air ... But the strains on our time are all so great.. [] It's difficult when you have one consultant one week, and then the other next week, for them all the time to share exactly the same views. It's a good way to run a ward but [] there may be some confusion from time to time [] among all the staff about what the total plan or outlook for the patient is.

I think the purpose of the meeting was to convince everybody working with her that we needed to be active and aggressive in treating her because all the evidence was that there was no organ system that was irreversibly damaged and there was still reasonable potential for her to become an active normal child.

PA: If she arrested you thought she should be resuscitated?

SR: Yes, absolutely. [He then said her condition worsened shortly after and so decisions had to change.] You've got to change with changes in the patient. But the idea of the meeting was that so many people looking after her were disaffected, disenchanted, er - bored - depressed They felt they were being cruel... persisting with the treatment, if she was going to die anyway.

I think any patient like that should be discussed so that everybody can be encouraged to remain optimistic to a reasonable degree, to know when to remain optimistic and to know what changes might be changing our optimism and our plan of action. The neurologist said he'd seen cases like hers who had recovered, so it was important to get the nurses to understand why we were persisting and try and increase their enthusiasm and their own optimism and therefore be able to cope not only with their own feelings but with the parents. [1.. If the nurse isn't convinced it's hard for them to be convincing. I think everybody needs a pep talk from time to time, ... even though the patient is very depressing. :

When doctors talk of 'managing a case' the case can include not only the patient's condition but the attitudes of the family and of the whole caring team. There was also the management of dilemmas. Choosing one course could entail rejecting valued elements of an alternative course, such as hope, a loss which no one could easily accept. Long term cases needed someone to take an overall yet detailed view, to make decisions or explain indecision in a way that could satisfy everyone caring for the child. Parents wanted to know that there was one person in overall charge, concerned and knowledgeable about their child and, as Mrs Williams said in chapter 4, that treatment was part of a whole plan and was not 'grasping at straws'. However, medical teamwork required loyalty to colleagues and deference to the various preferences and decisions of whichever senior doctor was on duty, instead of following through one treatment plan. The consultants also had to respect one another's decisions as 'perfectly reasonable' even if they would have decided otherwise. In risky and uncertain cases, continual cautious reassessment

might be safer than firm decision, but clinical caution could lead to social difficulties which needed as careful management as did the medical condition.

The following comments are all taken from a meeting about stress, attended by nurses and two junior doctors with the visiting psychiatrist. Although the staff said much the same to me in interviews, I have quoted from a meeting since this gives more evidence of consensus among the staff than private interviews would.

There was uncertainty within, as well as between, nursing and medical teams about sharing the work of informing families. SHO's were unsure how much they needed or were able to say. This comment by an SHO seemed to express a general view.

'We can explain simple things like a hole, but not complicated conditions, and operation risks or the prognosis. That's not our job. We're not cardiologists and anyway we don't need to explain, the parents will have been informed very fully in outpatients.'

SHOs were concerned with daily medical care of inpatients and informing families about these details.

In the next grade up, the one registrar at HH specialised in chest rather than heart patients. After nearly a year in post, a registrar was describing the long time needed to learn cardiology. They were talking of a child who had just died of endocarditis*, infection around an artificial conduit in her heart.

Reg: Shortly after the operation she had to be taken back to theatre. She was bleeding a lot where the conduit was connected to the heart. Maybe the infection was introduced then.

Psych: So why didn't they do their stitches tight?

Reg: Well the heart isn't pumping at the time. You can't tell until you've restarted the heart. Sometimes there's a clot or a stitch, or tissue gives way. Lots of problems can arise.

Psych: Would the family be prepared that it might not work?

Reg: I don't think surgeons ever talk beforehand in any detail. Cardiologists might do - very carefully in the clinic. [] In the clinic I'll speak in terms of mortality but not in terms of long term complications such as, "He might sustain brain complications and even be mentally retarded." It's difficult to know if you should spill all the beans. [] There are so many risks, it's enormous. Some risks never occurred to us. Maybe the consultants

knew, but we juniors didn't.

In several meetings I observed, there were discussions about problems of informing patients: the many risks and potential complications in complex surgery; difficulties for the large team of coordinating what they tell parents; how to talk in detail in the busy clinic when surgery is often still undecided and at some future distance; the gap between giving information, say percentage risks, and ensuring comprehension of mortality; and, in the absence of legal guides as in the States, the continual uncertainty about how much patients want or ought to be told.

These problems, well documented in literature on informed consent, are mentioned here to illustrate the continual awareness of the cardiac team of the many interrelated problems of informing parents. Problems often involved a choice between two essential values: giving full information yet avoiding confusion; deciding whether parents ought to be clearly aware of risks, or ought to be protected from having to agonise over traumas which might never happen. It is not possible to achieve compromise or complete harmony between these rival values. The staff had to decide which value to choose and therefore which to reject. For instance, consultants regarded ward rounds as important times for teaching and for sharing clinical decisions, purposes which made the rounds very long, leaving no regular time for other matters, and purposes best served by having large rounds of 12-15 doctors. Other staff saw that teaching needs could conflict with patients' needs. An SHO said at the meeting already quoted:

'When I first came I thought the rounds were awful. You can hear the quiver in fathers' voices when they try to talk, they're so intimidated by that big crowd, but there's no other time they can catch a consultant. After a few weeks I got used to it. I suppose doctors doing it for years don't see how hard it is for parents.'

And a nurse added:

'I particularly asked an SHO if the parents could be talked to during the round. They were very worried. Dr X [consultant] heard me and when they got to her bed he talked very nicely, and the parents got so much less tense and were very pleased and afterwards I heard Dr X say to the sister

that it was very useful. But why don't they learn and do it with the others? Why does the nurse have to ask?

There was concern not only about whether to tell painful news, but how to present it. The meeting continued:

SHO: I can't believe what's said on ward rounds. Such as, "Williams syndrome - do you know the incidence of mental retardation is 70%?" The parents looked aghast and were ignored but they looked as if they had never heard of it before. Then the next child - "The chances of surviving the operation are 30%." Christ, if it was my child I'd go mad.

SW: And the boy they said was only the second case in the world with that anatomy. His mother was ready to fall apart anyway.

Reg: That does happen a lot, we do rather take it for granted.

Professional awareness of the problems of informing parents was compounded by uncertainty that there could be any clear solutions, either in using standardised lists of risks or in systematic arrangements for determining who would give certain details and at which stage. The tertiary care and cardiac systems and also the varied needs of families seemed to limit the usefulness and the possibility of achieving precise routines. One doctor summed up the discussion quoted by saying,

'Parents seem to get told in dribs and drabs, elsewhere, through the tertiary referral. Some parents are difficult to tell things to, and some doctors are better at telling.'

Constraints on communication

Informed consent was easier when surgery was clearly advisable and successful, as if, like an insurance policy, it was satisfactory until the small print was put to the test. The psychiatrist pointed out a pattern in the meeting which, I observed, was common through the consent process - reluctance to talk about awareness of risk. The staff concentrated instead on knowledge as information, on what went wrong and why, but not on how they felt. Later in the meeting he asked again, about a child who had died, 'How are you feeling?' 'What was it like to be involved in her distress?' They then began to talk about being very sad, and the difficulty of knowing how to respond.

Reg: It's easy to talk when a child is well and bouncy but when they're very ill you feel awkward. It's very difficult. At the back of my mind I knew the chances of successful surgery were very small. Maybe some people can just be with a sick child and make them feel better. I don't know how to.

Nurse: It's always tough when the prognosis is clear to you but not to them. You can't say things like, "She'll be running around at home in a couple of weeks." It's hard to know what to say.

SW: I used to feel bad, guilty, partly responsible when a child was very ill. I feel that less now, but then I haven't got the role of making them better. Maybe it's worse for the doctors. I try to go to them and just be there, because parents say sometimes, "The doctors avoid us when they don't know the answers." I know I can't rush in and say, "You'll be better soon." It's not easy, but it's not so terrible. Touching the child, putting a hand on them is better than nothing. And I can go to my office but the nurses have to be there all the time.

Senior nurse: We've got more time than the doctors have to listen, and we can communicate without having to talk.

Male nurse: It's very difficult if there's not time to build up trust. I felt guilty about Tim (the 11 year old discussed earlier). He was increasingly depressed. I was asked to talk to him but there was never time. He needed to talk and we couldn't provide what he needed.

SW: I get very worried. What children feel passes unnoticed. We need a psychotherapist.

SHO: It's got to come from the top. It's very bad when they come in for an operation, they're talked to by SHOs who don't know the details in theory. The surgeons don't give the in depth counselling they deserve. They don't see a consultant when they come in and so the juniors can't learn by listening to the consultants talking with parents but that's an essential part of the training. There's no time. It's so highly geared up, there's such a rapid through-put. We all know and admit we don't talk as much as we should but nothing seems to change.

Cardiology is mainly directed towards clarity, precision, intellectual skills, providing a fast, efficient service and eliminating problems. When problems cannot be eliminated and children do not recover, a different response is necessary. The ability, for example, to tolerate problems which are very unclear, imprecise, hard to express or to intellectualise about, requiring time, patience and a relationship of care, 'just being with them'. Perhaps few people can combine such different activities as striving for cure and relating in care.

When treatment was not effective, communication between staff and parents tended to lessen. Parents spoke to me about becoming

more wary, anxious to know what was going on, and worried about being 'fobbed off' but feeling that they were being avoided. Medical difficulties had a compound effect. First, many parents became more pessimistic. One father said

'You hear of things happening to other people but it will never happen to you. Then sad things start happening to your friends, it comes nearer home, then it hits you. You have a child with a heart defect. You begin to realise that statistics mean you and you begin to dread what will happen next. You stop believing in good luck.'

Then parents noticed events happening to other children which they had not previously thought about. One father spoke of his shock when his new baby was in intensive care, and how he preferred ignorance.

'It's not a place where you'd ever want to be. You don't want to know about sick babies.'

Parents become aware not only of illness but also of medical problems in treatment. Darren's mother said to me:

'Maybe it's luck. Things seem to go wrong when we're in here. That little boy up in intensive care who's a complete mess. I feel sick.'

As if she felt she carried bad luck with her like an infection.

With a few parents I felt that I was intruding, that they wanted to be left alone, the interview was very heavy going, topics were continually closed off with a monosyllable or with a sad, bewildered reply, 'I can't remember', as if they needed to forget. I suggested, in chapter 7, that some parents seemed to need to be rescued from their isolation. This would involve not simply offering help but giving it in ways which were respectful, acceptable, not intrusive. Yet if parents seemed to be frozen inside their distress, any attempt to reach them could seem intrusive.

In CH, surgeons supervised postoperative care. Not all parents understood why the cardiologists, they had come to know before surgery, suddenly seemed to stop talking with them. The father of an eight year old in CH told me that his son was still unconscious two weeks after the operation.

'For years there was nothing they could do but now they have tried a new operation. [] The doctors seemed to be avoiding us after the operation, though before everyone would come up and talk. The surgeon said he'd come to talk to us afterwards but he didn't. We saw him a few days later and he just said, "Oh, we didn't expect it to go smoothly and it didn't." Well we didn't expect that, they didn't say anything to us before. His condition's a bit more complicated than other children but we thought he'd be out of the pump room after a few days.'

In trying to interview the despairing parents, I could see why the staff avoided talking with some of them. If treatment seemed to be failing, people were unsure what to say and how to say it. Cheerfulness could seem callous; sympathy could add to the gloom. Even simple things like asking how the child was seemed better left unsaid.

The paediatric cardiac team.

There are many parallels between the modern cardiac team and the sailor adventurers four or five hundred years ago, charting unknown territory, hoping for great gain but at high risk. It was necessary to ensure the loyalty of everyone involved in the venture. This loyalty depended on each person feeling sufficiently informed and respected (or afraid). Renaissance captains ensured obedience through clear leadership, agreed hierarchies and by punishing mutiny. Hospitals retain aspects of this kind of discipline. Yet traditional vertical hierarchies are being challenged by modern demands for horizontal democracies. The individual sister or consultant is being replaced by a group of sisters or consultants which partly dilutes their authority. Patient care is shared among many specialists, each through their unions and representatives demanding increasing autonomy and respect. Modern medicine, no longer able to command unquestioning obedience, has to inspire voluntary commitment. The democratic concept of informed consent, granted to those usually thought to be the weakest group, the patients, is perhaps one of the greatest challenges to all levels of the hospital hierarchy.

Information and respect, the central qualities which enable patients to become committed through giving their willing

consent, are equally important characteristics of the staff team. If some members of staff are uneasy about aspects of their work, this can undermine confidence and efficiency in the unit, adversely affecting patients and other staff.

Maintaining reasonable unanimity could be difficult among the very large team with constantly changing members and shifts. Like Renaissance ships, the hospitals could be uncomfortable places to work in. The staff were often overworked and tired by the night watches. Sometimes they argued over scarce space and resources. Perhaps the greatest challenge to unanimous commitment was that both ventures (medical and nautical) were on the edge of a new age. There was a tension between wanting the benefits of the new age of scientific medicine and, especially among the nurses, fearing it as alien and dangerous. Nostalgia for the old world of personal care in medicine and nursing conflicted with awareness of its limited ability to provide cure.

The quality of patients' consent was influenced by the quality of the staff commitment to each programme of care, by the amount of optimism or pessimism with which each nurse or doctor explained each procedure. Parents would talk about how potent nonverbal information could be: 'You could tell by that glimmer in his eye,' or 'You know by the look on her face.' This level of communication could have a strong impact on how confident parents might feel; it also could convey a nurse's underlying beliefs about harm or benefit very vividly. This is why an attempt has been made in this chapter to consider the *esprit de corps* of the cardiac team, their doubt or commitment, and their differing aims.

A major element in professional commitment was ambiguity: uncertainty about the effects of their work, its eventual harm and benefit, and self criticism that they were not achieving a perfection which they knew was impossible. It is therefore extremely difficult to give a fair account just by giving selected quotations from my notes which could give an oversimplified version of people's beliefs and criticisms. Each comment also had a particular context. Nurses' meetings could be angry and gloomy, yet this was a way of releasing tension in order to be able to continue with work which they believed was

very worthwhile. Comments varied on different occasions and the general morale, an elusive and subjective concept, was variously estimated. Nurses would say, 'It's been terrible lately, we've had a run of deaths, everyone's had enough,' or 'It's been quiet and we all feel better because we needed a break, but not if this goes on for too long, we'll feel low if we aren't kept busy.'

Because it is impossible to give a single, clear, overall assessment of something so complex and varied as the attitudes of the staff towards their work, only a brief and general review has been attempted in order to consider some of the basic patterns and influences on the consent process. Problems for the staff can be traced to four main origins. First there was the intractable nature of some heart defects, with the present limitations in diagnosis and treatment and the resulting stress for patients and for the staff who were trying to push back these limits. Secondly there were the human problems of a large group of individuals, with differing aims and needs trying to work in harmony. Thirdly there were hospital routines, many were essential and beneficial but some caused distress. Fourthly there were the personal limitations of each member of staff. No one felt they had enough time or knowledge, and inevitably choices had to be made between competing areas of work. This chapter has reviewed ways in which the staff negotiated sometimes conflicting interests knowing that each had indispensable claims. The next chapter considers one of the major means, trust, which enabled choices to be agreed.

CHAPTER NINE
RECOGNISING TRUST IN INFORMED CONSENT

*'On a huge hill,
Cragged, and steep, Truth stands, and he that will
Reach her, about must, and about must go; []
Hard deeds, the body's pains; hard knowledge too
The mind's endeavours reach, and mysteries
Are like the Sun, dazzling, yet plain to all eyes.
Keep the truth which thou hast found.'*

(Donne, Satire 3 on Religion)

Trust is often assumed to be an integral part of relations between doctors and patients, but there has been little discussion in medical sociology on the nature of trust and the contradictions in the ways in which it is experienced, expressed and interpreted with regard to high-risk surgery. There seems to be no sociological concept which embraces trust. In most work on informed consent, the nature of trust is assumed and its complications are not examined. Yet when consent is approached from the patients'/parents' perspective, trust is seen to present problems. I have therefore tried to develop a sociological imagination to examine trust, in spite of the practical difficulties of investigating it. This chapter examines contrasting conceptions of trust and how these influence the process of informed consent. The phrase 'informed and voluntary consent' implies that being informed and consenting willingly are complementary, mutually reinforcing experiences. Although this can be so, both elements can also conflict. The nature of trust as rational yet irrational will be considered.

Kohrman (1985:1092) believes that recent medical advances have occurred because physicians are willing 'to imagine effective lives for children previously thought doomed.' Expectations have changed so rapidly 'that there are many gaps in our understanding of societal impact, deficiencies in our ethical constructs, and excesses and imperfections in our practices.' Kohrman thinks that physicians are conditioned by 'believed prognosis' based on data or on guesses. To 'avoid prematurely foreclosing on hope,' doctors may encourage 'unwarranted optimism' which 'seems an even worse, crueller error.' Yet, Kohrman believes, the public are becoming aware of 'how uncertain, capricious and idiosyncratic

medical practice can be,' whereas formerly 'both medicine and its clients have collaborated in the mystification process.'

Informed consent may be seen as an effort to dispel mystification, and to open up medicine to lay understanding. Yet at the same time, new medical ambitions and complex knowledge can create new obscurities. Rapid changes in medical practice create problems for patients and doctors in how to sustain trust in the medical enterprise and also in their own ability to make valid judgements.

There is a long-standing debate in the medical journals on informed consent, in which the trusting patient tends to be set in opposition to the informed patient. The main arguments rest on explicit and implicit assumptions about trust. Doctors tend to trust in theoretical and technical knowledge, in utilitarian values, and in professional detachment. Parents however tend to trust in knowledge of their child gained through direct experience, personal values and involvement. The interaction of these two approaches is considered. The final part of the chapter looks at new ways of conceptualising experiences such as trust which involve learning to trust ourselves.

Trust as active belief

The slight discussion of trust in sociology is mainly concerned with its effect on behaviour and activity. (Simmel 1950; Loomis 1959; Garfinkel 1963; Henslin 1968) Trust will be considered here as an experience which, as Graham (1983) has shown concerning care (see chapter 2), involves both thinking and feeling, activity and identity, our essential existence and our consciousness. Trust is seen as a struggle, an active developing process subject to conflicting personal and public influences. This is an attempt to see rational and emotional constituent parts of experience together, 'to make phenomena visible' as Graham says, and to look at the sentient actor who is both conscious and feeling, while allowing that feelings are not wholly conscious. (Hochschild 1976:284)

Many of the problems of trust between patients and doctors also apply in sociology. Concepts of trust have pervaded all stages of this research, thus helping me to understand some of

the practical difficulties of patients and doctors trying to achieve informed consent. Questions of trust in research include those about: validity, verification and confidentiality; choice of theories and methods to use for selecting, reporting and interpreting the material with honesty and justice; how much anyone reading this will trust my work, or can be trusted not just to dismiss it but to attend to the meaning despite all the limitations of my account. The position of anyone reading this chapter and considering how much of it to accept, is like the position of patients and doctors considering information about proposed surgery. Most information has partly to be taken on trust, without demonstrable proof, if it is to be accepted at all. These questions of trust in research are mentioned in order to note the complications of attempting to explore trust through working practices imbued with its problems.

The notion of fully informed consent is fallacious because consent is given to a proposal about a future event so that all the consequences cannot be foreseen. Enlightenment concepts of truth, as scientific evidence, can obscure the subtlety and complexity of truth and our dependence, in obtaining information, on trusting our own confusing perceptions and other people's. Truth and trust share a root meaning of belief, and this older meaning of truth helpfully challenges positivist ideals of independent, objective judgement of facts. It reintroduces connections between object and subject, proof and faith, thinking and feeling, by acknowledging that we know through struggling to understand and partly through meanings we attribute to the perceived object.

Trust as rational yet irrational

Trust involves putting something precious at someone else's disposal, into their power. In relinquishing control over a precious possession, people make themselves vulnerable to the risk of harm, loss or betrayal. Two things of greatest value to parents are their child's welfare and their self-identity as their child's primary care-takers. These are the two key concerns of proxy consent to children's heart surgery which, to achieve its object, is damaging and has to exclude parents

from certain stages of care. One mother began a letter to me about consenting to her child's operation by writing:

'It is extra difficult to write about an emotional upheaval of such immense proportions. It is also somewhat disturbing to mention them as they tend to be pushed to the back of one's mind. To many parents this must be one of the most traumatic occasions of their lives.'

The parents in the cardiac units seemed to experience trust as an activity, partly conscious and rational, partly unconscious and emotional. Trust works as a kind of hinge by which parents move from the mode of questioning independence and rational assessment of risk into the mode of voluntary consent, a willing suspension of questioning doubt and independence. A patient going for surgery is like someone who has decided to jump off a burning building, having checked as far as possible that the building is burning (diagnosis), that there is no other way out (alternatives) and that there is a safety net (prognosis). Eventually the only way to test the truth is to take the risk, to entrust oneself helplessly to the skill of those holding the net. Trusting feelings of faith and hope enable patients to risk danger; trust is part of the force which impels patients to choose surgery as the lesser danger.

There is a contradiction between reasoning quests for information, and trust in which critical reasoning is suspended. Yet trust is also part of the earlier stage of informed consent. Reasonable discussion between doctors and parents can develop only when each believes the other to be talking and listening honestly, without deceit or concealment, with respect for the other's viewpoint, and when each can risk giving confidential information, asking 'silly' or intimate questions or admitting ignorance, trusting that they will not lose the respect of the other. Trust enables relationships to be tested and developed, paradoxically through taking risks in making seemingly mistrusting, critical challenges. For example, asking for a second opinion appears to express mistrust, but can lead to fuller acceptance of the first opinion if it is confirmed.

The proxy position is complicated by questions about who is the best judge of the child's interests, especially if these may

conflict with the family's interests. Doctors' beliefs that they ought to act as the child's advocate can restrict them from confiding openly in parents. For example, the parents of a baby of 10 months, did not want her to have palliative surgery which would keep her alive only for a few years, and might lead to 'the nightmare' of a series of operations which could not cure her. The baby's father wanted to protect her and the family from this distress. The consultant wanted to keep open the option of surgery, reminding the parents that the child's interests must come first, and warning them of future distress. They might later want to choose life-prolonging surgery but find that progressive lung disease made this impossible. So the consultant put forward arguments for surgery, but said to me when the parents had gone: 'It is very difficult for all of us. The parents are set against surgery because they know there is no cure. I think they've been brave enough to do what I would hope to do but I'm not allowed to say.' This implied that in order to keep faith with the child, the doctor felt an obligation to counter the parents' arguments and to keep open the option of surgery by not entrusting the parents with a personal viewpoint.

In discussions about surgery, two forms of doctor-patient relationships intersect. Patients who question the doctor as teacher, for example, about the cause and nature of the disease, express trust in his or her expertise. When patients question the doctor as provider of treatment, and ask about the effects of interventions, it can be difficult for them to avoid implying suspicion about medical skill. They risk alienating doctors when they are dependent on their goodwill. They increase their insecurity, not only because they fear *appearing* to the doctor to be mistrustful, but also because they fear *being* mistrustful when they need to nurture their trust on which they will have to depend. As risks increase, fear may inhibit questioning because the higher the risk of death from surgery, the more likely are patients to die without treatment. Opinions differ on the appropriate balance of information and trust, and the time to switch from questioning autonomy to vulnerable faith. Some parents said they questioned more carefully on behalf of their child than they would on their own behalf. A proxy fits uneasily

between patient and staff, intensely sharing both the patient's fear and risk, and also the staffs' responsibility.

Signing the consent form is not necessarily a sign of complete transition from doubt to assurance. Mixed feelings may continue for long afterwards. Although parents may believe in the doctors' good faith that they gave the best possible advice, this is not the same as being certain that the treatment benefitted the child. Trust is a process of transient states which eventually resolve into certainty about harm or benefit. Perhaps the fullest analysis of trust or faith has been made by religious writers who believed that, after resurrection, relative faith would resolve into absolute certainty; modern surgery offers a close analogy. Trust is a mixed, ambiguous tension between doubt and the hope of certainty. Several parents said, 'I won't relax till he's safely home.' One mother wrote that months after her daughter had died she still had nightmares about subjecting her to painful treatment. Yet equally parents were tormented by guilt, a form of mistrust in their own capacity to care, unless they could feel satisfied that 'everything possible had been tried'.

Whereas some staff seemed to interpret consent as completely entrusting the child into their care, for many parents their responsibility partly continued. For example, the mother just mentioned wrote of her relief that she was able to keep her promise to her four year old daughter:

'that I would stay with her until she had had the anaesthetic. [] If my child had died during the operation as far as she knew I would have been with her.'

Trust and doubt

The example of Janet illustrates parents' problems both of moving between doubt and hope, and also of fidelity - fulfilling their obligations, towards their child and the staff caring for her. A long example is given because it summarises details repeated in many of my interviews with parents: the changing process of consent; how mothers' thoughts tended to differ from fathers' thoughts about surgery; the struggle to reconcile technical information with awareness of risk; how adverse feelings and contradictions may have to be gone through in order to arrive at

a state of trust; problems with making sense of contradictory advice and fragmented care at different hospitals in the tertiary care system; delay in being able to believe in success.

Janet's diagnosis and treatment plan were gradually agreed over many months of prolonged uncertainty. Mr and Mrs Green talked with me in the ward five days after Janet's successful surgery. She was their fifth child and had Down's syndrome and an atrioventricular septal defect.* This major defect is often not detected or diagnosed at first. Doctors disagree about the best treatment for Down's children with this defect and may leave a larger than usual share of the decision to parents, so that this example is of unusually long and full discussion.

From the beginning, the parents felt some doubt about medical information and reassurance. They told me that when Janet was born, doctors 'suspected she might have a murmur but on further examination they couldn't find anything so they felt that her heart was all right'. When she was two weeks old she suddenly stopped breathing and doctors thought that she had choked, but later her parents were told this was probably due to her 'having such massive heart disease'. Knowing that Janet had not choked, her mother thought that the doctors 'who were extremely kind' wanted to prevent her from worrying about cot death.

M: But I never believed them. I would have preferred to have known what really happened, but then I don't know if they knew themselves..

E: I think the condition wasn't easy to diagnose early on... it seems to show up after quite a few weeks.

M: I mean this was always the story we were given - Oh, I won't say 'the story', this was always the version we were given to believe.[]

The example shows anxiety as an inevitable part of awareness of the child's problems. Instead of being made worse by medical information, anxiety can be exacerbated when doctors avoid discussion or offer reassurance which parents do not believe. A tension is set up between needing to trust doctors and disbelieving what they say, between feeling anxious and appearing to be reassured and trusting.

In time, Janet attended five hospitals and her parents were offered different diagnoses and medical opinions. At four

months, Janet had an echo* and the whole defect was first diagnosed. Expecting to be told that Janet had only a VSD*, Mrs Green thought that 'the consultant was very kind but he was very truthful and at the time we just couldn't take it. Once he told us the actual diagnosis, I think we shut off, because when we got home we couldn't really remember an awful lot of what had been said.' There were three options: high risk corrective surgery; lower risk palliative pulmonary banding, (which was likely to lead on to further surgery either another band or a correction); or no surgery, which would mean that Janet was likely to have a fairly healthy childhood but would die of lung disease in her twenties or thirties.

M: He said at that stage we wouldn't have to make up our minds to do anything, and that we would come back and discuss it further. In retrospect, we both would have loved to have come out, gone for a cup of tea, talked about it, and then been able to go back in and question him again... I think we would have asked him to repeat it all over again, because I came out in tears, very upset.

At first Mr and Mrs Green were against corrective surgery, feeling that the risk was too high. Janet continued to be unwell and very difficult to feed. At clinics, doctors advised on different options and discussed in detail the risk and benefit of each one. Eventually Janet's parents 'took the emotional choice' to have surgery, but left 'the medical decision' about the type of operation to the doctors. Yet trust and doubt both continued. As they were bringing Janet into hospital for the banding operation, her parents were reading a book about Down's children with Janet's defect. (Jane & Stratford 1985)

M: It was fantastic because it actually said they didn't recommend banding.

E: For an AV canal.

M And that in fact was what she was coming in for as we were reading the book.

E: On the way to the hospital.

M: Because we were only given it that morning. Someone who had helped to write it rushed it to us from London. [] When she was admitted we saw various doctors, who said they didn't want to do the banding.

E: Quite independently of what we said, we didn't influence them at all.

M: It was just coincidental that there we were reading the book in the morning thinking, "Gosh! what are we doing? We're having our child banded and there's this book saying

"Don't". It really said it could cause more problems than it could solve.

E: Although it could rest the lungs, [and he explained technical details].

PA: What would you have done if the doctors wanted to band?

M: I think we would have trusted the doctors.

E: We would have trusted the doctors at the time. [] It's all very well reading up about things in medical books but when one really comes down to it, one puts one's hands in the doctors' in the hospital here.

This example shows how parents, especially the fathers, feel obliged to learn about technical details, yet they still rely on doctors to interpret the details, to set the essential considerations in an order of priorities, and to relate them to the particular child. Again, the decision was postponed and Janet's parents continued to 'thrash about and get as many books as we could'. As with many other parents interviewed, Janet's father wanted the higher risk correction as he thought that technically it was an appropriate solution, whereas her mother, despite knowing about its disadvantages, wanted the banding because 'I just wanted her a bit longer without having to face the risks.' At 11 months Janet was readmitted and her consultant decided on corrective surgery.

E: He thought her chances were better than 4 or 5 to 1, so he upped them.

M: Yes, he put her at 8 or 9 to 1 that she wouldn't survive which really was quite a good risk to take.

E: That really did sway us because we were grappling with 4 or 5.

The encouraging news was accompanied by depressing news as if to show that with complex surgery, whenever arguments support one decision, other arguments can always be advanced for the opposite case, and it is hard to see the total picture of all the factors and their relative importance. Janet's heart was so small that there might not be enough tissue to rebuild the two valves, so that she might need artificial valves and later more surgery to replace them as she grew.

While signing the consent form, Janet's parents still felt uncertain and were told by the surgeon, 'Oh yes, you can back out the minute before she goes down.' Mr Green 'plucked up courage' to sign but, as many other mothers admitted, Mrs Green did not

have 'the courage to actually put my name on. If it had gone wrong, I don't know how I would have felt.' Janet's parents seemed to need faith in their decision as well as technical reasons.

F: We had several talks with doctors and also with our minister. He counselled us and made it very clear that whatever decision we made it would be the right decision because we were making it in Janet's interest, not for any other motive, so whatever decision we came to, we felt that was the right decision and we couldn't possibly reproach ourselves for it.

M: Even if she had died, I think in time I would have accepted that it might have been the right thing, but I don't think I would have done then.

Giving formal consent was not seen by parents as a decisive stage signifying completely trusting commitment. Anxiety rose before and during the operation. Janet's mother said,

'I sat up with her through the night before, holding her. [] When she was in theatre [] your mind is just not anywhere, and you're clock-watching the whole time, thinking, "What are they doing now?"'

Janet was in the theatre almost two hours longer than expected and her parents waited in the chapel 'trying to be composed'. Her mother said that when they were told Janet was back from the theatre,

'It was the most wonderful, marvellous news. It was absolutely incredible. They managed to repair all the valves out of her own tissue. It's like a dream still. I keep saying I can't believe it's reality. I just never thought she'd come out of it.'

Learning to believe in cure was a process of gradual adjustment, the rearrangement of beliefs, similar to the previous process of coming to accept the need for surgery.

Information or trust

In the medical discussion about consent (summarised in chapter 2) some authors ask why patients want to have information and a share in medical decisions unless in 'bad faith' they mistrust medical competence and benign judgement. Caring doctors are presented as those who shield patients from distressing news and choices.

LeBaron(1985:56) deduced that paternalism promotes a positive psychological and medical outcome and that abortion patients prefer 'a childlike dependency [with] intense feelings [] that the physician is powerful and reminiscent of [] a kindly, loving parent.' Patients treated in an egalitarian manner may feel abandoned, and would 'retain a critical, evaluative attitude.' Paternalists argue that patients are handicapped both in their reason and their emotion because of their ignorance and anxiety, (Brewin 1985) and they want not simply information but also wise advice. (Laforet 1976; Inglefinger 1980) Brewin (1985) adds: trust 'means less risk of misconceptions' and is also a 'marvellous time saver' because it can be a substitute for long explanations. Doctors should therefore be good leaders, and 'improve morale' with a show of confidence, 'not just blindly dish out "complete honesty" and tell everybody everything they "have a right to know"'.

Anxiety

Much research on informing patients is based on dualism, assuming that doctors are correctly rational and active and as a corollary patients are emotional and helpless, ignorant, and liable to make deluded decisions. In reports, doctors' information tends to be metamorphosised into patients' anxiety, and so is measured not for the quality of the information but by whether patients' anxiety rises or falls and so by implication whether trust (viewed as the opposite of anxiety) is encouraged or undermined. The usual assumption, that anxiety should be avoided tends to lead to negative conclusions about informing patients. Klaus (1985) theorised that parents' 'over-anxiety' in response to having 'too much information' could harm their sick baby by causing parents to stop visiting the hospital.

In research on parents' 'coping strategies' in an ICU, two nurses assumed that parental anxiety should be suppressed by parents' internal mastering of anxiety 'to maintain effective equilibrium'. (Miles & Carter 1985:15) Their questionnaire offered parents passive options, such as, 'being allowed to stay', or 'being provided with hope', (a question which is meaningless out of context). Semi-passive options included 'trying not to let myself get too emotional'. If the nurses had perceived anxiety as a moral reaction to the actual stressor, the child's suffering, and as a potential source of heightened understanding of the child's needs, the nurses might have offered parents active options and a greater share in caring for the child. Significantly, parents said they found most helpful 'being permitted to stay with my child as much as possible', whereas 'going home to rest' was found to be 'the least helpful'.

Medical doubt

Research on medical information giving usually measures only patients' anxiety, and does not consider the powerful motives of doctors wanting to avoid discussion of disturbing information. Clinicians are likely to mistrust anxiety because it raises awareness of the human costs of treatment. In order to be able to continue their work, they need to contain awareness of harms and of patients' distress, to sustain their faith in the benefits of treatment, and to concentrate on the goal of cure. American paediatricians were found significantly to underestimate risks of medical procedures. (Janofsky & Starfield 1981) Frohock (1985) has shown how a course of treatment which is *intended* to benefit is considered by doctors as beneficial and therefore not harmful. Distress is likely to be discounted in medical equations and, I suggest, in the very language of 'risk/benefit' which stresses certain benefit against uncertain harm. Inverted, a similarly loaded phrase would be harm/hope. American studies have shown that physicians report greater fear of death than that reported by control groups of patients. (Aring 1968) This suggests that doctors may accept higher costs of painful treatment, as a worthwhile means of postponing death, than patients would choose.

There are many pressures on doctors to support their own and

their colleagues' credibility and to inspire confidence in their patients. They do this partly by supplementing rational analysis of the vast body of taught and textbook medicine, most of which they have not time to test, with trust in overall medical efficacy. They concentrate on physiological activity which is easier to assess and manage than the patients' feeling states. The surgeon in chapter 6 suggested that personal contact with patients brought emotion dangerously nearer to conscious awareness; keeping families at a distance was a way of controlling this. Abstract theory offers a refuge. Yet assumptions which mistrust engagement, which is the basis of parents' knowledge of their child, may denigrate practical knowledge gained from the low status work of child care, in preference for respect for the theories of high status medical authorities. Superior scientific expertise may be conflated with superior moral judgement, leading to the response of one cardiologist who said, 'Oh no, we cannot leave parents to make that terrible decision, we have to make it for them.' Another cardiologist told me:

'I consider that we are paid to make decisions, it's part of the job. If parents agree their child should go to surgery and the child dies, they will blame themselves and it's a decision they have to live with for ever afterwards. Sometimes it helps if they can blame someone else. I think we have to accept this. [] I try to present the choices without bias but that's impossible, and it's all an opinion as to what we all said. It's all in the mind and very difficult to assess.'

Paternalism and attempts to relieve parents' burden in medical dilemmas have vital elements of compassion. Many parents may need this relief. However, there is the risk that elements in paternalism of mistrust, of assuming that patients/parents are incapable, will prevent doctors from listening to people who do want to share in decisions. Parents cannot wholly be freed from guilt, and this may be exacerbated if they have consented to procedures that they are not satisfied they understood or agreed with. A bus driver's wife said at HH,

M: I want to know all the intricate details for myself, as if I could do the operation. I can cope better if I know. A lot of parents don't want to know, but doctors should be able to tell the type of parents they're dealing with. Some

of them think that all parents are dim. I'm not saying I don't trust doctors, but they tell you lies by omission. If I hadn't read the books I don't think I'd know anything.

I think they have no *idea* of the trauma you go through. I think it is diabolical that no one tells you after surgery how it went. I chased Dr M and he said it had gone quite well and the valve they thought might be leaking wasn't when they went in so they left it. I wasn't told they suspected a leaking tricuspid valve until Sunday evening although it was seen on an echo six months ago. On Sunday they said they might do the valve. That made me much more worried. When Chris had Fallots* corrected, afterwards they said to me, "We've left a small hole but it will close on its own." That was the hole they closed on Tuesday. Now they're telling me they've left the leaking valve... So it's like a nightmare, a repeat of the first time. Is it alright or isn't it? I think overall that paediatric heart surgery is only palliative, which is quite depressing.

PA: Do you tell Chris? [aged 7]

M: I don't say this to Chris.

PA: Might you, when he's 17 or 27?

M: [Long pause, she looked shocked] I can't visualise him at 17 years old. I think it's pretty obvious they're not going to live till they're 90. [] I don't think doctors are on the same wave length. They just try and stop you worrying - unnecessarily as they think.

Consumer and health movements and the media offer much information to parents, so that, for those parents who want to be informed and involved, fuller discussion with doctors seems likely to encourage trust and reduce mistrust.

Maguire documents how hospital staff unconsciously but 'consistently use distancing tactics with their [dying] patients to try to ensure their own emotional survival.' (1985:178) He concludes that if staff are 'to risk getting close' to patients, they could be harmed by the experience unless they are supported in developing personal and team-work means of coping with the strain. Themes of risk and trust run through his paper in the problems of overcoming fear of oneself, of patients and of colleagues, in order to be able to talk openly about distress. As a nurse said in HH, 'I am personally very frightened of dying and find it hard to cope with the older child dying because of my fears.' The ability of doctors and nurses to risk talking about painful issues with patients, and to trust patients to respond positively instead of purely in criticism or despair, may have some relation to professionals' trust in themselves. Their unease can arise from mistrust in two main areas: first, in their

personal and professional ability to respond to the patients' pain, fear or grief; and second, in doubts about contemporary medicine, how much harm does it cause, how much good does it achieve. In these two areas, concerned with the means and the ends of medical practice, misgivings perhaps most commonly and urgently arise in specialties such as intensive care of children, where mortality and morbidity rates are high, treatment can be distressing, and long term benefits uncertain.

Doctors persuade as well as inform. Innovative medicine partly depends on doctors conveying optimism to patients and colleagues, and avoiding doubt. Writing about neonatal care, Kohrman (1985:1095) explains the dilemma.

'We have been on a technophile course in medicine; both the promise and the limitations of technology for the solutions of the eternal human problems are just now coming into focus [raising new problems. Intensive care medicine] is the most visible testimonial to the limits of and the problems created by technology [and doctors] are necessarily the most committed believers in its possibilities. They [] can serve as lightning rods for the frustration and anger of a society in the process of adjustment to disillusionment.

Frequently I was aware of undercurrents of doubt in the units. Nurses and social workers spoke of the stress in cases of prolonged uncertainty about whether a child would die or be permanently brain-damaged. In outpatient clinics, after families had left, some consultants would tell me the risks and adverse side-effects of treatment, and of their frustration at not being able to alleviate problems. After a series of such patients, one consultant said to me, 'Sorry, a disastrous morning.'

Mistrusting patients

Patients are expected to trust doctors, yet trust may only be possible when it is reciprocal. Some doctors' trust in parents was limited. One consultant said:

'I don't expect much of parents. In episodic events I may rely on them, but I tell them what is likely to happen, that the child may become blue, so if it does happen they are reassured that I knew it was likely. There has to be trust between the parents and physician, to reassure parents that you know what to predict. It's a way of handling it and involving parents. I don't rely on their opinion. I prefer to go on objective clinical data. I assess the likely

progress and plan accordingly. Parents want to know how we can manage it.'

Here, trust is conceived like information as one-way not as mutual; parents trust doctors' objective expertise, yet doctors mistrust parents' subjective 'opinions'.

Some consultants felt it would be wrong to trust patients with certain information. After one fifteen year old left the clinic, the doctor said,

'I can't see any future in people knowing they may suddenly die. That's a little bit of medical paternalism. I don't know how explicit to be about the risk of sudden death but I think talking of a dilating aortic aneurism* gives them a flavour.'

Trust involves respecting the other person's viewpoint. If doctors did not appreciate the child's view, trust between child and parents could be undermined. Terry aged three was crying at his postoperation clinic check.

Mother: He's frightened just a little bit but he's doing fairly well.

Father: He's a mummy's boy and we can't get him away from her. [] He cries a lot. Do we walk away and leave him crying a lot at playgroup?

Consultant: Oh, what you'd do with any other child. My own son got up to the same tricks.

Mother: It's trusting people that's the problem. Oh, have you got our new address?

There were four reasons why his parents could have responded to Terry's crying as a serious sign of distress, not as 'tricks'. Terry was unsettled by his recent operation, by moving house, starting at a new playgroup and his mother had just had another baby.

Trust as duty or a reaction

Paternalists advise that:

'Doctors need freedom to act upon their judgement of what is best for their patients. [] Morally speaking the relationship ought to involve trust on the part of the patient and fidelity on the part of the doctor.' (Dunstan & Sellar 1983:111)

This advice, as is common in medical ethics, implies that 'what is best' is not subject to doubt or disagreement. Yet if there is only one best course and if doctors always follow it, informed consent is a polite token of respect but not a necessary precaution against suffering; it is ornamental but hardly useful. Patients' mistrust is also made to appear irrational and unjust. Yet trust may not be a duty which we 'ought' to feel, but an involuntary reaction to certain criteria which we cannot help feeling. Sociology needs a clearer understanding of the nature of trust when discussing doctor-patient relations. Since trust is not directly observable, it may partly be understood by using Freud's method of showing feeling through allegory. In a biblical story (Numbers.22) Balaam, a prophet on important business, is riding his donkey along a narrow way. The donkey stops and refuses to go on although Balaam beats and threatens to kill her. At last Balaam realises that she has seen an angel standing in their path, pointing a sword at him.

MacKenna (1987) suggests that Balaam represents authority, all the rules and theories we are expected to follow. We are the donkey, burdened down with all that we 'ought' to do and believe, but occasionally aware of truths which contradict Balaam's instructions. By linking trust and ought, paternalists tell us to trust Balaam in the form of medical authority. Yet this can mean denying new awareness in which we cannot help trusting and which inevitably causes us to doubt authority.

Trust can be seen as more than a passive response, say, to medical activity. Trust in her awareness of the angel, impels the donkey to act by making her own rules. If defined as an obligation, trust can turn into a form of coercion, a reason for not informing patients, and a source, for doubting patients or parents of guilt and inner conflict, as Jane's mother felt in chapter 4. Trust then moves from being a source of awareness (of the angel) to being used as a means of suppressing awareness, (as Balaam tries to do when insisting that the donkey obey his authority). Concepts of trust as a duty deny its dynamic and involuntary nature as a powerful feeling, so deeply part of our identity that it cannot be static and institutionalised in the way much medical ethics suggests.

The notion of medical fidelity can be used as a further restriction on patients' critical judgement. Fidelity means keeping promises, but the trusting patient is expected not to exact promises and instead to leave the doctor freedom of choice. This can shift the meaning of medical fidelity into keeping faith with impersonal medical ideals which may differ from, or even be hostile to, patients' personal preferences.

Trust as a personal relationship

To many parents, their sense of the doctor's character and attitude towards their child was extremely important. Doctors expected families to trust in the tertiary medical framework rather like trusting in an institution 'as safe as the Bank of England.' Parents tended to assume a personal meaning of trust, and wanted to know that a particular doctor had a personal concern for their child. One mother told me how her child had almost died when in the care of her local doctors and was dramatically rescued by expert cardiologists. Yet she still trusted her local paediatrician in preference to the cardiologist who was

'too cut and dried. There was no warmth or compassion in what he was saying. He didn't relate emotionally to the child. I always feel happier seeing our paediatrician [because he seems unhurried and humble]. He's very positive and can handle the negative side very gently. The heart is very technical but I think cardiologists could handle it in the same way, positively and gently.'

At first, this attitude seemed to me illogical. Yet as I heard more parents talking about the value they placed on warmth and respect I began to see how they wanted to trust doctors to take the child's view into account when making decisions and providing care. At HH the father of a girl aged six with Down's syndrome was worried that her operation was postponed several times although 'she was being sent home from school with blue attacks every day.' Her mother wanted to show trust and said to me:

'Every time they cancelled we'd put on this smile and say, "Oh, that's okay." But there was that lack of respect, no thought for your feelings. I think that's made us a bit bitter. We do this underneath thinking, what we really think about letting loose and getting aggressive, and on top

we tend to be polite. We're not the sort of people who want to create a fuss.'

Eventually they protested and Diane had her operation. Her discharge was delayed because she refused to eat.

Father: She is very unhappy. I'm convinced if she did go home she'd start feeding. We've known her for six years and we really do understand how to look after her. But the ward round all stand and talk, then tell you what they've decided.

I think the doctors ought to go on a course for bedside manner. Someone comes running around, has a quick listen to her heart, a quick look over. Like it's, "Those are lovely conditions for us to work with." He's not bothered, because she doesn't communicate. It's a case of she's a lump of meat lying there so you roll her about a bit, you drag her off down a room and forcibly take some blood off her. You're not able to relate to it [the child] so you just sort of ignore it and carry on. If parents dare to create a stink then they get the same treatment.

Mother: We, um, it was very wrong of us but we started getting a bit paranoid.

Jacobs (1979) shows how denial of child patients' emotions contributes to their distress. In impersonal treatment of the child as a work object, the staff work to technically high standards but they do this by avoiding close relations with the family. The units I observed were far more open and welcoming than Jacobs' hospital. Yet there were still barriers which expressed underlying mistrust between staff and parents.

Boundaries to trust

Formal and informal barriers to parents' access have been mentioned in chapter 7 and others are described in the attached reports. An example is the 'ordeal' of the ICU intercomon which one father wrote became 'the focus of all the anxiety you feel about how you will find your child so we are bound to hate it'. (Bereaved parents' report p7-8). Two parents said they were asked to wait after their child had returned from theatre and then they were forgotten. One said she waited in suspense not daring to ring again for 'the longest two hours of my life'. There were also invisible barriers restricting mutual trust, (such as described in the bereaved parents' report p4-5). A father wrote of the difficulties for everyone of talking openly

and sharing feelings about death, in the impersonal context of ICU where death is the ultimate failure.

Nurses who tried to be close to families could find it very hard at times. A senior nurse told me how sometimes when a child died,

'I feel sort of shaking and not really knowing what to do or where to turn and wanting to run away. Sometimes the parents have supported me almost. [After one child died, his mother] just came and put her arms round me and said, 'Oh, Bridget, I'm glad it was you that was here. [] In a sense ... my shell had gone ... Whereas if they thought we didn't care it would be easier but it would be wrong. I'd rather us show our feelings... I try not to wear a shell but I always want it to be around ... Well, it's - what do soldiers wear? A sort of shield. It's very seldom I need to resort to it.'

Compared with studies in the 1960s and 1970s, nurses in the cardiac units in the 1980s shared awareness sensitively with families. Yet, especially in ICUs, the staff were still uncertain how far they could trust anxious parents to become an accepted part of the unit. Fear can engender deeper understanding and trust. One mother in CH described how acknowledging, rather than ignoring, anxiety helped her to cope with her fear.

'Like doctors - some have a better way than others. One said to me, "I think we're fighting a losing battle here." It was just her temperament, but I thought what a dreadful choice of words. One doom merchant said, "You do realise how ill your daughter is?" Of course we do. You want to be told the bad and the good things. Most of the staff as people are okay. Martin's the best doctor you could have. He came over to tell me personally. He's human. He feels for you. You can talk to him. You feel attached to them, you've been through so much together. You're so dependent. They take their time to go into detail. Start with the good news and then - "but we'll have to be very careful." Somehow he's got the right way. He's frank. Not some kind of tin god but he's a dad as well on the same level.'

Parents' concern with personal awareness described in earlier chapters was also part of their perception of trust. Care in giving information suggested to parents care in relating to the child and family, a quality which parents wanted to see in the staff they entrusted with their child's life.

The synthesis of technical and personal care is criticised, for example by Foucault and others concerned about medical surveillance. Yet poststructuralist theory could be interpreted as extreme fear of involvement with one's self and with other sentient beings. The theories contribute to understanding of medical oppression, but if they are used to conclude that excising personal issues from medical encounters is a means of avoiding oppression two problems result. One is the expressed need of many parents to include personal issues, they cannot divorce the technical and the personal. The other is that denying the personal can leave unresolved anxiety which may be relieved when explicitly discussed. The following example of such reassurance is taken from a very relaxed discussion in which the mother and doctor gave me an impression that they shared amusement about the policing role of medical surveillance. Simon was thought to be 'inoperable' and was sent back to his referring hospital. To everyone's surprise he survived his first four months so surgery was attempted. At nine months, after two major operations, he attended HH outpatients, grotesquely thin but cheerfully smiling.

Mother: With weight gain - er - or not weight gain. Any idea how much I should expect him to put on, or when I should worry, or not worry?

Doctor: I think we're more concerned with whether he looks well. If he's smiling and responsive and not pale and sweaty.

M: Right.

D: The weight gain *per se*, I wouldn't use that as the only indicator of well being. Er, is that?

M: Yes, that's a lot better. [Laughs] Er ...

D: Well, obviously we'd like him to - well people use weight as an index of health ...

M: Mmm

D: And as an index that the parents are looking after the child properly and all that.

M: Yes.

D: We have no doubt about all that. [Both laugh]

M: I keep waiting for someone to phone up and say, "That mother's starving her child."

D: [Laughing] That's right. [] He might put on weight in the second year.

M: Oh well, at least we might get there. That's the hopeful thing.

Running through the explicit talk is implicit acknowledgement of the mother's anxiety that she may seem negligent and that her son may soon die. As well as being technical, the doctor's words are also expressive, confirming and moderately optimistic. The transcript cannot convey the sense of shared understanding through the whole encounter. For example, sentences did not need to be finished in order to be understood, and many were begun by one speaker and finished by the other.

Part of the need which many parents seemed to bring to the cardiac units was for reassurance about their felt inadequacies, both in having a child with a heart defect and in the care they gave their child. The opposite view to fear of surveillance is expressed by Buber.

'In human society at all its levels, persons confirm one another in a practical way in their personal qualities and capacities and a society may be called human in the measure to which its members confirm one another.

The two-fold basis of our life is: the wish to be confirmed as what we are, even as what we can become, by others, and, our innate capacity to confirm one another in this way.

That this capacity lies so immeasurably fallow constitutes the real weakness and questionableness of the human race; actual humanity exists only where this capacity unfolds.' (1957:101-2)

The final part of this chapter considers how trust in doctor-patient-parent relationships can confirm those involved in what they are and what they can become. Whereas inequality and paternalism can reduce awareness, certain interpretations of trust may increase awareness of the child's needs and of the adults' ability to respond.

Trusting patients and parents

Arguments in favour of informed consent, summarised in chapter 2, may be grouped into four main kinds: abstract theories of respect; empirical evidence that patients want to be informed; concepts of consent as a defence against unwanted medical interventions; informed awareness as part of therapeutic adjustment to illness and treatment. This section considers the fourth argument.

A major objection to informed consent has been that it may

increase patients' anxiety. However, increased anxiety has been shown to be a source of growing understanding which can aid adjustment to procedures, and can aid physical and psychological recovery. (Wallace 1986; Denney et al 1976) Wallace concludes that information can nurture trust when 'informed consent can be [] a therapeutic process, involving emotional preparation, a sense of control and helping the patient to have realistic expectations of the staff and hence perhaps less disappointment after the operation.' (1986:29) She indicates a long history of this approach with a quotation from 1767:

'it is reasonable that a patient should be told what is about to be done to him, that he may take courage and put himself in such a situation as to enable him to undergo the operation.'

Kubler Ross (1969) shows how the most effective care for dying patients is achieved when patients and staff can trust one another enough to talk through their negative feelings towards peaceful adjustment. Information may not increase anxiety itself; it may only increase overt expression of latent anxiety which patients are relieved to be able to express in order to seek help and to dispel unnecessary fears. Clough (1979:77) considers that the meaning which patients, (in his study, girls in an orthopaedic ward), construct about their illness and treatment, vitally affects their expectations and perceptions of treatment. Children reacted with pain and hostility, or with appreciation of benefit depending on their understanding of treatment. Clough advises using a psycho-social logic to study relations between patients' behaviour and their disorders of meaning. Kelly (1987) shows the crucial importance of patients' informed and voluntary consent. In his research, patients' acceptance that treatment was necessary and beneficial enabled them to adjust to ileostomy and helped to prevent damaging, bitter regret felt by those who remained unconvinced of the need for surgery long after having an ileostomy.

Groups which advocate informing patients are mistrustful of paternalist doctors who reserve for themselves not only information but also, therefore, the major share in making medical and personal decisions for patients. Harrison's paper,

(1985) on the parents' role in decision making in intensive care explores problems of trust in medical technology, and considers that parents' anxiety can be an appropriate, rational warning signal. She summarises over 70 examples of neonatal medical research and treatment incurring high risk and questionable benefit, which illustrate scientific and ethical problems. One example is Andrew, born at 25 weeks gestation and kept alive for five months despite numerous problems with his lungs, heart, brain, eyes, stress ulcers, amputation of a gangrenous leg, rickets and breaking of fragile bones. One doctor remarked that Andrew needed the ventilator because with all his broken ribs 'it hurts like hell every time he takes a breath.' His physician threatened to take legal action against Andrew's parents 'immoral' requests to let him die. (Stinson 1979) USA legislation in 1985 'to mandate treatment for all infants considered potentially viable' means that American parents can no longer refuse treatment of the type given to Andrew. (US Federal Register 1985)

This is an extreme illustration of problems in American neonatology, which is different from cardiac care in this country. It is given because it so clearly raises the dilemmas for some parents in the cardiac units about whether to allow their child to go on suffering and whether they should always trust in medical treatment and decisions. I saw a few apparently hopeless cases of children having weeks of intensive care, and heard nurses saying that some children were kept alive for too long, but I was unable to ask parents if they would choose to end treatment. The longer the effort, the more difficult it could be to admit that it was all in vain. Some parents may be more cautious about treatment than doctors are, others may be more anxious to prolong their child's life with drastic treatment. Parents and doctors both rely on knowledge and personal opinions when deciding when the physical, emotional and financial costs of prolonged treatment out-weigh the potential benefit. Disagreement among the medical team demonstrated that this could not be a purely clinical decision. Harrison contended that:

'in order to protect our children from abusive over-treatment [or] discriminatory undertreatment...parents can take steps to enter the decision-making process ... by fully

informing ourselves and others about the complex ethical problems created by neonatal medicine. [This would include] rethinking policies, no matter how well-intended, that promote withholding information from parents or that effectively deny parents access to divergent medical opinions.' (Harrison 1985:172-3).

Those who advocate informing and involving parents assume that they can be trusted to understand medical information and to use it to make wise decisions. In order to make, in the words of the Nuremberg Code, 'an understanding and enlightened decision' parents may be guided by values which extend beyond clinical judgement.

The concept of consent is founded on theories of respect for the individual person. An integral part of respect is trust in the good sense of that person. Paradoxically, Enlightenment thought advanced *conscious theories* of respect yet, by denigrating emotion, it undermined *subconscious practical* respect for ordinary thinking, feeling individuals. Recognising the part of trust in informed consent enables us to see the unity of reason and emotion in the consent process. I suggest that the distance between the ideal and the practice of informed consent will remain until rational feelings are understood to be a valid part of our identity and a valid source of knowledge. When doctors, patients and proxies acknowledge the integrity of human nature, in themselves and in others, mutual respect and reciprocal trust, the necessary bases of adequate consent, will become possible.

CHAPTER TEN

CONCLUSION

'Is it better to "think" without having a critical awareness, in a disjointed and episodic way? In other words, is it better to take part in a conception of the world mechanically imposed by the external environment, i.e. by one of the many social groups in which everyone is automatically involved from the moment of his entry into the conscious world. [] Or, is it better to work out consciously and critically one's own conception of the world and thus, in connection with the labours of one's own brain, [] take an active part in the creation of the history of the world, be one's own guide.' (Gramsci 1971:323-4)

The value of patient consent depends on whether patients or their proxies can be informed adequately about medical proposals, whether they can make decisions with reasonable freedom, and whether the consent process can contribute to the welfare of the patient in promoting the benefits and preventing harmful effects of treatment.

Informed consent Although some doctors thought that parents could not understand decisions about surgery, others, cardiologists and surgeons, worked on the assumption that parents can and do understand the nature and purpose of proposed surgery. Quotations in the thesis indicate something of the great care I observed taken by some doctors, nurses and parents to share this knowledge and to sort out the principles, essential in making reasonably informed decisions, from the mass of technical details. Many parents who explained their child's surgery to me, appeared to have a clear understanding, (as far as any lay person, including a sociologist, can judge), of the essential principles. Not all parents wanted, or felt able, to be informed.

Throughout the thesis I have argued that informed consent involves more than transmitting technical information. The consent process involves growing awareness of the child's medical and social needs which is achieved when doctors and parents share their knowledge so that both sides are enabled to make more fully informed decisions.

Voluntary consent Voluntariness is the most elusive, neglected and difficult part of consent to research. I have

considered theories which point to means of uncovering less visible and conscious issues such as voluntariness through interpreting observations and interviews. Each theory needs to be explored further. Examples throughout this thesis demonstrate the practical limitations surrounding attempts to practise the democratic ideal of voluntary consent within traditional hospital hierarchies. Simply teaching doctors clearer methods of giving information will not enable parents to give freer consent. Recent efforts to ensure that patients are more fully informed need to be accompanied by efforts to ensure that they are also more fully respected, valuing greater equality of status as well as of knowledge. This would require major changes in hospital routines and professional status, aiming to enable rather than to control patients, if reasonably voluntary consent is to become possible.

Adequate consent Describing consent as 'adequate' or 'good enough' denotes a realistic approach to what is possible within the unavoidable limitations set by the patient's disease, the present state of medical skill, and the patient's ability to understand medical knowledge. Assessment of levels of adequate consent will always depend on the criteria of the assessor. Satisfaction may rest on low expectations rather than on adequate experience. Even if the criteria of 'adequate consent' are agreed, many problems for empirical assessment remain, beginning with critical analysis of the research theory and method. My research was an initial exploration and has produced more problems and questions than answers. Yet it has produced a clearer understanding of the consent process and has begun to outline a framework which could be used in hospitals and also for further research.

In order to understand consent, we need to regard it as a whole process, which can only be seen when contradictory elements which are normally separated in analysis are drawn together, such as; the medical and the patient experience; reason and emotion; technical information and personal awareness; respect and care; researcher and research subject. Within this qualitative approach, doctors' and patients' criteria for adequate consent may be recorded and considered in relation to observed practices.

Consent is not just one formal moment. Signing a form before surgery entails more than the appearance of agreement. Consent needs to be seen within several interrelated levels. It is an inseparable part of the practical working relations between families and staff, the character of the individuals involved, of the institutional setting and, more widely, of the developing character of modern medicine and parenthood. It is influenced by the quality of preceding discussions within a doctor-patient relationship which may continue for years and may involve numerous small interventions to which families submit with varying degrees of voluntariness or coercion.

Unfortunately, present concepts of informed consent are centred at the extreme end of medical care - surgery, in which patients are least knowledgeable. Arguments are then dominated by such questions as how much lay people can or want to understand medically. *The opposite approach would be to ask in which areas of hospital care are patients knowledgeable, to which issues do they most want freedom to consent or dissent, such as in the patient's daily routines, feeding and pain relief.* When meals are handed out by the playworker, often only parents are aware of the effects of nauseous drugs on appetite. So necessary knowledge is lost when making medical decisions unless parents are encouraged to be part of the caring team.

Informed consent is in danger of being treated like a game of chess. When champions challenge novices, the likely result is to show the novices' limitations. There is then a risk of concluding that novices are generally ignorant; that patients and proxies are ignorant in all aspects of medical and nursing care as well as in the most complicated parts such as diagnosis and surgical techniques. Many parents arrive at a similar conclusion from the other direction; if their opinions pass unheeded in small matters, they do not expect to be able to influence major issues. If they do not feel free to look for a chair, how can they question a surgeon's decision?

When I asked parents explicitly about consent to surgery, some looked blank as if they unquestioningly left such specialised matters to doctors, but had plenty to say about the quality of their child's care. A study of consent cannot be confined to

medical definitions of informed consent as consent to major procedures. It needs to include the practical 'minor' issues in which families see their involvement and consent as very important and often as more informed than the judgements of hospital staff. Parents are concerned not just with information and treatment but with *the way in which these are provided*, the quality of care, the hospital setting, the contradictions between what they expect and experience. In these, beneficence, justice and respect for the child's autonomy were crucial issues.

Children's consent

My main omission has been children's informed consent to surgery. Assumptions that children cannot be informed and involved reinforce damaging denial of their needs, and research in this area is necessary. Children's law is based on two values which are assumed to conflict: children's need for self-determination and for nurturance. Yet these values may be reconciled when parents enable their child to develop self-determination through the way they nurture their developing skills. Proxy consent can enable children to have an increasing share in medical decisions. The value of proxy consent needs to be understood not, in Lord Denning's phrase, through 'parents' dwindling rights' but through research about children's growing responsibilities and how parents can help children to defend their own interests.

Attempts to consider children's views are complicated by the risk of harmful intrusion and misunderstanding, and by difficulties of eliciting their views, and of evaluating them. Who can decide when a child feels so isolated and depressed by a limiting condition that he or she would chose very high risk surgery? Yet parents spoke of being strongly persuaded by their adolescent children. A mother who was horrified at the suggestion that her son have a heart transplant said that he persuaded her to look forward to the operation. Another mother described how things went 'horribly wrong' when her daughter had months of treatment for endocarditis* and two aortic root homografts.* 'I groaned when the cardiologist said the new aorta would only last about ten years, but Sarah said, "Oh Mum, it's all right, you're only ill for a few weeks."' An eleven year

old was determined after months of endocarditis that she wanted to refuse surgery and go home to die. After they had persuaded doctors to agree and she had died at home, her parents were convinced that they had helped her in the best possible way. Another 11 year old was taken to theatre for what proved to be fatal surgery, shouting, 'I don't want to die today, Mummy.' Nurses discussed his case for weeks afterwards, saying that he should have been prepared and consulted.

Children had strong and varying convictions about living and dying, and research suggests that children as young as five clearly understand concepts of death. (Lansdown & Benjamin 1985) Some children would be further protected, and parents' sense of guilt and betrayal about consenting to risky treatment might be eased, if children were formally consulted and if, as is being recommended in Western Australia (Rayner (1987), from the age of 13 they sign the operation consent form.

Research about improving the proxy consent process

The most useful kind of research about informed consent is likely to be experimental, trying new ways of informing and involving parents, to work up from the known to the unknown. The three surveys attached to this thesis contain many such practical recommendations. Other ideas could be added such as the following three ideas tried in other hospitals.

1. Parents are taught how to share in as much skilled and intensive nursing care (giving drugs and injections, recording observations) as they feel capable of doing. (Nottingham)

2. Records are held by outpatients, resulting in more informed patients and fewer mislaid files. (St. Thomas's maternity clinics.) Parents could keep a record book with space for the diagnosis/assessment and treatment plan agreed at each clinic including drug doses and next appointment. Parents could fill in the details with the consultant, clinic children's nurse, or one of the observing doctors.

3. Each child has a qualified primary nurse responsible for the continuing overall programme of care. (Royal Marsden) The nurse is on first name terms with the family, encourages close and equal relationships, listens to their problems, criticisms

and anxieties, and also ensures that the medical teams listen and are accountable to the family.

These examples have been given because they are innovations which entail questioning professional hierarchies and traditional mistrust of patients and parents. Family care has been found to improve when professionals work to increase not undermine, parents' confidence and ability. Nurses are the key people enabling these changes, bridging the gaps of knowledge and of authority, drawing doctors and patients closer in patterns of shared care, communication and decisions. Junior nurses' anxiety about families' distress can be used as a source of knowledge which helps to raise standards of care.

Changes are continually being made. Siblings are now allowed into HH ICU, and a telephone has replaced the intercom. After the initial stress, and once accepted, change can increase satisfaction for the staff. 'Having child visitors lightens the atmosphere in ICU,' said a senior nurse who believes that changes in practical care are the means of changing attitudes. Yet at CH, the ICU is now far more difficult to enter, new formal barriers have been introduced. CH has just launched a £30 million appeal, blaming old buildings for restrictive practices, but this denies the crucial effects of attitudes. Mistrust still impedes advances in care and therefore needs to be recognised. I suggest that it is founded on the conflict between concern for scientific precision, efficient objective detachment, and concern for personal care based on trusting involvement, the value of which cannot be measured in cost-effective terms of time and money saved or factual knowledge gained. Some doctors and nurses fear being deceived or coerced by personal involvement and by feelings - their own or their patients' -, whereas some patients fear being deceived or coerced by doctors who value science above care. MacIntyre's view (1981) that choosing one course can mean losing valued parts of the rejected course illuminates how the ideals of scientific detachment are hostile to the practice of compassionate care and total compromise may not be possible.

Consent, benefit and harm

Consent is a vital meeting point of the two ideals of science and

care, enabling doctors and parents to discuss and potentially to share the choice of direction. This can happen if, in Gramsci's words (1971:323-4), we are ready to think with critical awareness, not just in a disjointed and episodic way, but aware of the tension between science and care, and taking an active, conscious part in making choices. Commenting on Gramsci's thoughts, Seidler wrote, 'People are constantly struggling against the dehumanising conditions in their lives', 'against the concrete conditions in which they are forced to live'. (1980:117). The struggle in cardiac units can take opposing directions, each course valuing children's lives but in different ways. While some nurses and parents strive to make hospital care more humane, protecting children from harmful interventions, doctors tend to struggle against 'the concrete conditions' of mortality and morbidity, extending medical skill, sometimes by using painful, aggressive and impersonal means.

Modern science and technology, although intended to serve our convenience and safety, have been criticised as destructive and life-wasting as, say, in industrial pollution or the nuclear arms race. Paediatric cardiology would seem to be quite different from, even a vindication of, much technology because of its nurturing and life giving aims. However, cardiology shares some destructive, dehumanising methods, such as in its mutilating surgery or oppressive institutions. Frohock (1986) argues that current emphases on rights to life and treatment conflict with a baby's more basic right to tolerable life and freedom from harm.

'Benefit' and 'harm' are open to subjective interpretations, so raising the question as to why parents' concepts of benefit and harm should count in medical decisions. There is growing knowledge about harm and benefit to children in hospital. The benefits of parental care in hospital have been explained, (for example by Bowlby 1953; Robertson 1958; Klaus & Kennell 1976; Petrillo & Sanger 1978). Benefits include: preventing emotional deprivation; providing the consistent personal care which young children need; acting as interpreters between the child and the staff and as advocates for the child; filtering experience which might otherwise overwhelm the child; encouraging children to perceive treatment as beneficial. Each of these activities

relates to informed consent. Parents' ability to contribute to their child's care depends on how well they are informed, respected and consulted by the staff, how fully parents are convinced of the value of treatment and how willingly they support medical decisions.

Parents may also be important in reducing preventable iatrogenic harm, using their consent as a precaution against their child's suffering. It is estimated that one in ten patients is admitted to hospital because of problems caused by medical treatment. This proportion is likely to be higher among young children, the least robust of patients and also the least able to alert hospital staff to adverse effects of treatment. Jane Williams (chapter 4) was one of several examples I observed in which her mother's presence seemed to be linked with her recovery. Some babies, with problems similar to Jane's and whose mothers were with them for much less time during admission, deteriorated and died. More research is needed into how parents in hospital contribute to their child's clinical, as well as their emotional and physical, care and how they help to prevent harm.

The parents' continuing care, unlike the staff's fragmented and impersonal view, means that proxy consent is not 'just another adult's opinion' because it can be based on *unique and essential* knowledge of their child. Although not all parents put their child's interests first, many do, and no satisfactory substitute has yet been found to replace inadequate parental care, except the closest possible substitute. So at present, most children's best hope of their interests being represented rests with their parents. Parents' knowledge of the child is unique because it is an intense, continuing, personal involvement with the child. One mother, whom the nurses thought was 'very simple, she doesn't really understand', told me:

'I'd feel more guilty and upset than the doctors would, because I'd signed the form. They're only doing their best, their job. But how would you feel if something went wrong with your child on the table? The doctors don't see it like that, that he's my child. They think I'm moaning. I'm not complaining but I have a right to know, to be told what is happening, the good and the bad, and what his condition would be if he didn't have these operations. A heart operation is serious. I feel really guilty when I look at

his scars. I've really got to have second thoughts about whether to say "no". Mothers really should have more say than doctors because you have to carry it all. When he's back home, I do everything. He's mine. I have to take responsibility for him everywhere I go.'

This mother saw her right to be informed and to dissent, not in terms of (property) rights for parents, but as a means of fulfilling her responsibility to her child. She saw her work as a mother to be at least as important as medical work. She depended on medical information, yet she could influence medical opinion. Talking with parents can moderate doctors' views, and in being accountable to parents, doctors have to consider their own decisions more carefully, and to become more aware of harm and risk. When harms of modern medicine are acknowledged, parents' anxiety may be perceived as appropriate, rational, a protection for the child and a source of understanding through thinking and feeling deeply about the child's interests. Interests are interpreted not as arbitrary preferences or wants but as basic physical, emotional and moral needs.

Parents challenged the common prejudice that anxiety always reduces rationality, by talking of how anxiety could raise their awareness of the inestimable worth, to them, of their child, and their longing to make the best possible decision. One father, an actor, quoted lines from *Much ado about nothing* which expressed for him the meaning of giving consent to high risk surgery.

'For it so falls out
That what we have we prize not to the worth
Whiles we enjoy it, but being lack'd and lost,
Why then we rack the value, then we find,
The virtue that possession would not show us
Whiles it was ours.
When he shall hear she died upon his words,
The idea of her life shall sweetly creep
Into his study of imagination
And every lovely organ of her life
Shall come apparrell'd in more precious habit,
More moving delicate and full of life
Into the eye and prospect of his soul
Than when she lived indeed.'

His triplets had been close to death several times and he added, 'There were so many moments when we didn't know if those little girls would ever come through. We want to say, "Oh, take care of

that baby," when you see someone bashing a pram around Tesco with a fag hanging from her mouth, it just kills us.'

Children are so dependent that they are liable to suffer if their interests are considered too much as separate from, or in conflict with, those of the family. Mercer (1986:197) gives an example of a child who had spent all his two years at CH and had more than 20 operations. The child's surgeon (not cardiac) commented,

'They are outstanding parents. Many people would have cracked, their marriage would have broken up, they would have abandoned their child.'

When beginning on the long course of treatment for the child's seven defects, this surgeon did not ask for parents' informed consent. Neonates are routinely sent into his unit with a blank consent form signed by the parents. A blank form is also used in cardiac units. Doctors at CH told me:

'Usually a form is brought in with the baby. Most often the problem is known and the form is for - well they would know it's for heart surgery, not just for anything. But sometimes it has to be general, permission for any investigation or treatment we think is necessary.'

Modern medicine increasingly puts pressure on parents to 'give the child a chance' through treatment, whatever the cost. (Dickens 1985) Yet it is questionable how far medical benefit can compensate for the psychological trauma to the child of being abandoned. In some cases, family breakdown may be a sign, not of weakness, but possibly of a reasonable response to inappropriate use of technology. Sometimes the only course for parents may be to leave a situation which they find intolerable because they have no power to prevent their child's suffering, and worse still they feel partly responsible for it. Parents' sense of guilt for congenital defects is widely recognised. (Bentovim 1980) Parents' can also feel guilty about the child's treatment because they have given consent. If consent is not reasonably informed and voluntary, signing the form can be, worse than an empty gesture, a form of responsibility without power. Instead of being a means of protecting patients from coercion and harm, the consent form may become a means of coercion, forcing parents to

agree in ignorance to decisions which later cause remorse. In rare emergency cases when it is impossible for doctors to explain decisions to parents, it would be more honest and respectful to dispense with the consent form.

The effects of surgery cannot be certainly predicted. A low risk operation may lead on to months of intensive treatment, which if it could be predicted, might never be embarked on. Careful discussion beforehand in every case, even in potentially low risk cases, may reduce the frustration of powerless responsibility in helping parents to believe that they shared in making the best possible decision.

Conflict in definitions of harm creates the need to develop new ways of acknowledging the value of both rational and emotional responses, such as compassion, to children's suffering; an interaction which brings growing understanding if we can trust ourselves and one another. Instead of being regarded as a result and a consequence, informed consent as a process becomes a means of working towards better care of patients, of continually growing awareness of needs and the means of answering them. This includes seeing the extra stress for the staff as parents become more involved in care and finding ways of helping both the staff and the parents to cope (as suggested in our nursing survey attached).

Gramsci considered that contradictions occur when

'a group has, for reasons of submission and intellectual subordination adopted a conception which is not its own but is borrowed from another group [] when its conduct is not independent and autonomous but submissive and subordinate.'
(1971:327)

Rather than attempt to prescribe general, external answers to medical dilemmas, medical ethics and sociology need to show underlying problems and barriers, and to raise awareness of how to perceive the individual patient's experience, and the inequalities which prevent open discussion. Then informed consent can be valued as a power to moderate scientific progress to a pace which accommodates care and respect for individual patients, by making doctors more accountable and aware of the effects of their work on patients. Gramsci continued:

'Critical understanding of self takes place therefore through a struggle [] of opposing directions, first in the ethical field and then in that of politics proper, in order to arrive at the working out of a higher level of one's conception of reality [] towards a further progressive selfconsciousness in which theory and practice will finally be one.' (1971:333)

Gramsci knew that this could be a lonely and painful process, through a 'sense of being "different" and "apart",' as Jane's and Diane's parents felt when they reluctantly began to criticise their child's care. Awareness begins 'in the ethical field' through moral anxiety about inadequate care. This may be resolved through the 'politics' of negotiating for better standards.

We need medical practice, training and ethics which acknowledge the value of parents' critical awareness of their child's needs, and which respond to parents' knowledge. The ideal theory of informed and voluntary proxy consent will then be more nearly one with the actual practice of consent.

APPENDIX
GLOSSARY OF MEDICAL TERMS

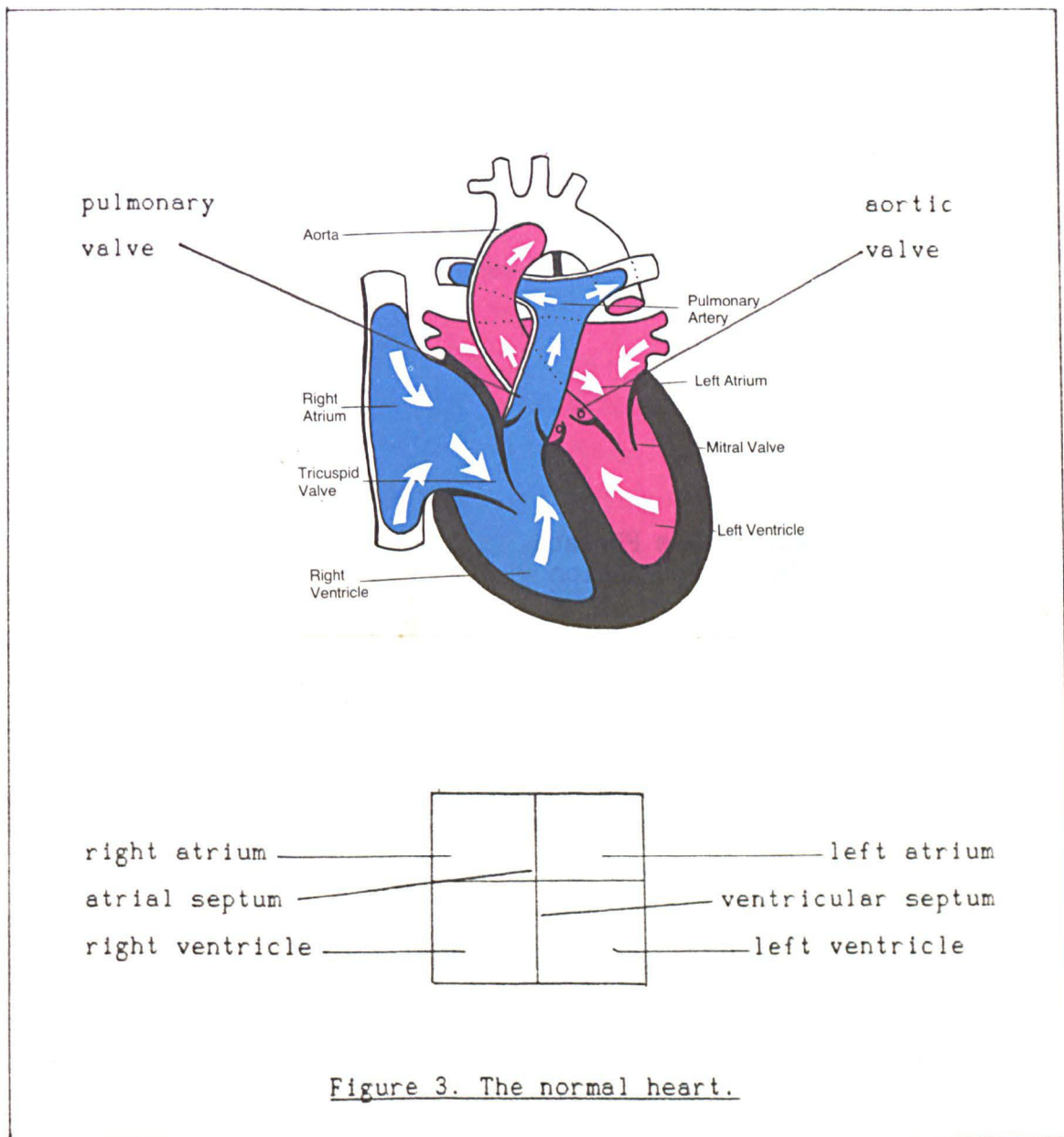


Figure 3. The normal heart.

Aneurism Swelling of a blood vessel which may burst.

Angiograms Xray moving films taken during catheterisation.

ASD - atrial septal defect Hole in the septum or wall between the atria.

Atrioventricular septal defect/canal defect The central part of the heart is missing and the four chambers work as one. Correction includes closing the ASD and VSD and constructing tricuspid and mitral valves.

Banding A stitch is tied round the pulmonary artery to reduce blood pressure on the lungs and enable the lung arteries to grow. If the pressure were not reduced, in resisting high pressure, the arteries would remain or become too narrow. Bands may have to be removed or replaced as the child grows.

Bypass surgery The heart and lungs are stopped and the patient is linked to a heart and lung bypass machine during the operation. Confusingly, shunts are sometimes referred to as 'bypass surgery', because they are inserted to bypass an obstruction, although the bypass machine is not normally used during a shunt operation.

Cardiac catheterisation A narrow tube is inserted through a vein or artery in the groin up into the heart in order to measure pressures in the heart, to take blood samples, and to inject xray opaque dye which shows up the heart and surrounding blood vessels on film. Anomalies can then clearly be seen. Children had a general anaesthetic for catheters in one unit, and were sedated in the other.

Cyanosis Blue condition or blue 'spells' due to lack of oxygen from poor heart function.

Diuretics Drugs to increase the flow of urine are much used in cardiology to reduce body fluid and hence reduce the work load for the heart. They can affect children's weight and appetite.

Double outlet right ventricle - DORV The aorta and pulmonary artery both arise from the right ventricle.

Echocardiography A transducer is rubbed over the chest, passing sound waves through the chest which are converted into images of the heart on a television screen, as in scans used for pregnant women.

Endocarditis Infection in the heart which is fatal if an effective antibiotic cannot be found. Bacteria from the mouth are associated with endocarditis, so dental care is often discussed.

Homografts Tissue or organ of human material inserted into the patient. Other types of grafts are allograft, (parts used from the patient's own body), xenograft, (animal tissue) and grafts of man-made fibre or metal.

Hypoplastic left heart The left, and normally stronger, side of the heart is undeveloped. This defect is almost always not treated in the UK and the child usually dies within days of birth.

Palliation Surgery which relieves problems caused by a defect but does not correct the defect.

Pulmonary vascular disease Lung disease, when the lung arteries remain too narrow so that surgery which improves heart function, sending more blood to the lungs, can do more harm than good. This is a progressive and fatal disease and a central concern in cardiology is to prevent or control it.

Septectomy A hole is cut, (or in a septostomy it is torn), between the atria (during catheterisation or surgery) to enable red and blue blood to mix. This is done for defects, such as Transposition, which prevent blood circulating around both the lungs and the body, and which cannot be corrected at that time.

Shunts connect two blood vessels in order to redirect the flow of blood.

1. A hole is made in each vessel and they are stitched together (e.g., Potts and Waterstons which are no longer done).
2. The end of one vessel is stitched into the side of another.
3. A graft or small tube is stitched on to connect the two vessels; these shunts are made of human, animal or man-made material.

Tetralogy of Fallot Three defects, a VSD, a narrow pulmonary valve, and the aorta overriding (lying over) the VSD, combine to cause extra work for the right ventricle which becomes thickened - hypertrophied. The aorta takes blue as well as red blood round the body and the child becomes gradually more cyanosed.

Transposition of the great arteries The aorta and the pulmonary artery each arise from the wrong side of the heart. They are transposed, creating two closed circuits, so that blue blood circulates between the body and the right side of the heart, and red blood circulates between the lungs and left side of the heart. Treatment, after an early septostomy, is either to patch and reconstruct the heart chambers in order to redirect the blood flow (Mustard's, Senning's operation) or, in more recent cases, to disconnect the arteries and switch them over into the correct chambers (Switch operation).

Truncus The aorta and pulmonary artery form a single trunk. Some types of truncus are almost always fatal.

Valves The four valves act as lock gates. They may be too narrow (stenosis), blocked (atresia), or leaky (incompetent).

VSD - ventricular septal defect Hole in the septum or wall between the ventricles.

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- (Abbreviations: CUP - Cambridge University Press;
OUP - Oxford University Press; RKP - Routledge & Kegan Paul;
BMJ - British medical journal; NEJM - New England journal of
medicine; SS&M - Social science & medicine;)
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CARE OF CHILDREN WHO HAVE DIED AT THE BROMPTON HOSPITAL
AND CARE OF THEIR FAMILIES

This is a combined report of the views of bereaved parents and also of paediatric nurses on the care offered at the Brompton Hospital to dying children and their families.

90 parents whose child died at sometime between January 1984 and March 1986 were sent a letter from Sue Rees asking for their comments. (Copies of the letter, the question list and a note about the administrative arrangements are in appendix 2.)

The recent nursing satisfaction study of the views of 74 paediatric nurses, carried out by Bridget Comer included questions about terminal care. (For a note on the questionnaire method see appendix 1.)

The parents' and nurses replies are reported in different ways. The nurses ticked replies to 21 direct questions which are shown in tables, and they also added comments. The parents were asked to reply to 12 general, unnumbered questions in their own words. Some parents wrote letters or gave long answers to some questions and left others unanswered.

We do not claim that the parents' views are representative, partly because each experience is so individual. Their comments are reported at some length in order to indicate something of the range of satisfaction and need.

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We would like to thank everyone who has contributed to this report.

Sue Rees, Paediatric Social Worker, Bridget Comer, Clinical Nurse Teacher,
Priscilla Alderson, Sociology Research November 1986

RESPONSE RATES

90 letters were posted to parents.
There were 18 replies, a return rate of 20%.

74 questionnaires were personally given to nurses.
There were 58 replies, a return rate of 79%.

In both studies the returns could remain anonymous.
All the parents added their names, only one nurse did.

The ages of the children concerned:

3 were less than 2 weeks

4 were 2-4 weeks old

1 was 11 weeks

1 was 11 months

3 were 1 year old

2 were 2 years old

The other children were aged 3, 4, 6 and 13 years.

PARENTS' VIEWS

The parents wrote of the pain and difficulty of replying and the hope that their letters might be of help to others. One grandmother who answered for her daughter sent £150 for the ward.

1. WAS THERE ANYTHING ESPECIALLY COMFORTING WHICH HAPPENED AT THIS HOSPITAL?

Parents felt encouraged when the staff helped them to have confidence that their child was having the best possible care.

'The nursing staff gave us the feeling that our son was being well cared for. The doctors with their professionalism gave us confidence. Also the fact that Mr Lincoln himself discussed the operation with us made us feel that our son was in the best hands.'

'The hospital is large, busy and unfriendly but certain nurses were a great help.'

'The doctors and nurses were all very sympathetic and very efficient, but still had time to talk and be very nice.'

'We felt that everything that could have been done was done and the staff were very compassionate.'

'There had been an underlying question how far to keep her alive at very high levels of support just hoping, without much confidence, for some improvement. Finally there was nothing left. In retrospect I think the staff handled all this well. Everything possible was tried, as we wished, but we did not feel the burden of any decision. When she was allowed to sink it was without any fuss (to use too strong a word).'

'I cannot think of anything in how we were treated which made things worse than they were bound to be. But I do recall feeling often then and later how kindly we were treated by everyone.'

'We struck up a friendship with many of the nurses.'

The parents also appreciated practical help.

'I was able to stay with her all the time, which I had promised her, as I had a bed in her cubicle in ICU. I shall always be grateful because it means that I did keep my promise.'

'People were extremely kind in finding us beds if we had to stay the night unexpectedly. There are difficulties in admitting siblings to the unit I know, but people were accommodating, and at the end the nurses took care of our [visiting] younger daughter for us completely.'

'We have the utmost praise for all the staff. We and our son were allowed to be with our baby whenever we wanted. This was especially comforting.'

'The doctor who asked for our consent was helpful and considerate, and Sue Rees was a great help in sorting us out financially as I was unemployed.'

'We regularly got up to date information and our wishes were taken into account such as lotions to be used on the baby. The breast pump room was small and cosy which helps if you are a 'doubting Thomas'.

Some parents felt that touching and holding the dying child was important

'The comforting thing about him dying was that I was allowed to let him die how I wanted, which was in my arms, in bed together with no wires.'

'It was a comfort to know that when he was breathing his last breath the sister held him and she assured us of this.'

Parents appreciated the extra care taken by the staff

'The one thing that stands out was the christening ceremony, organised by the sister in the early hours without any complaint.'

'Our priest was allowed into PICU almost every day to bless her which meant a great deal to us.'

'My wife and I and my parents were able to be with the child before and after his death. It was a great comfort that one of the staff accompanied us to the car afterwards.'

'I think the care we received was lovely and sensitively done. It was important to cuddle our child afterwards and a priest gave her the last blessing and prayers and she was baptised when she came to the hospital by the same priest. The night sister was superb and she put all little daisies around her little cot. It was very touching to see it. In the months that followed it is these personal touches that have helped me to come to terms with our tremendous grief and sadness.'

'We were touched and moved by the care taken to lay her out in her shroud while we were out telephoning and being given tea. It might seem odd but we wished we had had a camera.'

'A wonderful nurse helped me wash and prepare my son afterwards.'

'The room had subdued lighting and she was lying in bed holding a small flower. We were given time on our own and were encouraged to hold her and were also offered photographs of her.' 'The photographs which sister took and we took have been a great comfort to us.'

'One very touching thing was a few weeks afterwards we had a postcard from one of the nurses who was in Lourdes. This was one instance of times when the staff showed their own emotional response.'

Four parents said they could remember nothing comforting.

2. DID ANYTHING HAPPEN WHICH WAS PARTICULARLY DIFFICULT TO COPE WITH?

'It was all difficult to cope with, but not because of anything anyone said or did.'

Difficulties in communication

'The loneliness and fear and worrying about my other three young children at home 200 miles away. Her illness was so rare I seemed to know more about it than some of the staff, and certain doctors seemed not to realise that I did have enough intelligence to know something about the illness and my daughter's response to some treatments. I had nursed her every day from the very early stages before any doctor would recognise that she was ill and I resented being tolerated as something that had to be humoured and put up with.'

'A senior doctor told us in full view and hearing of other parents that he did not think our son would make it through the operation. We said we would not give our consent and he informed us that if our son did not have the operation he would die. After the operation we kept asking the doctors, and they kept telling us, "He's fine and his blood gas readings very good." Later we were told the machine was giving the wrong readings and they weren't good at all. We asked, and were told that the machine would not make any difference to our son's condition, but even though I have no medical experience it seemed to me that it must make a difference of some sort.'

'My baby was only at the hospital for a few hours. The worst part of it all was sitting in an office waiting for the diagnosis. Perhaps it would have been better if the hospital had somewhere to wait in more comfort. The staff were as helpful as they could be under the circumstances.'

'Our baby was admitted only an hour before he died. We had to wait in an office and would have preferred to wait in the same room. When they realised nothing could be done we sat in a separate room with him and held him and were given time on our own. Staff kept coming in to offer comfort but we did not find this intrusive. Taking into account we were like strangers to the staff, we were satisfied with the service.'

'After our son had been in theatre more than 8 hours we asked a nurse for information and were told, "The surgeons cannot stop the bleeding." This information should not be given by nurses but by a doctor with tact.'

'The only thing going through our minds was success with the operation was 95% - the surgeon had said, "Looking at the positive side, - 95%"'

'One of the surgeons stressed the high chance of failure and asked if we had any other children, as if, if our baby died it wouldn't matter so much because we had two others. Probably it wasn't intended but it could have been placed in a different order.'

The difficulty of talking

'We always felt the deaths of other children keenly. Of three children who had major surgery one ill-starred day, a little boy died one week later, another 3-4 weeks later and our daughter 7 weeks later. The first death was when we were in the small waiting room one evening. It was quite evident what was happening. Later we travelled down in the lift at the same time as the parents. I wanted, badly, to say something, but didn't. That was partly because the child's mother turned her head to the wall,

whether she wanted, or felt she ought to hide her tears I wondered but did not know. That I didn't say how sorry I felt was my fault. But I think there were pressures not to speak which were unfortunate. Noticeably people in the waiting room were too nervous, often, to ask how your child was. Equally, most of us I think found it easier when we did talk. (Some of course lacked fluent English. They might have felt more isolated if the rest of us felt less.)

'Within the unit staff were naturally reticent. It may be that not remembering a loss is necessary in order to cope. But I wonder if there was a policy of not readily acknowledging that another child had died. There can be no ethical requirement not to show emotion in those circumstances, as I see it. For my part it could not add to my worries for my daughter. And when she died I did not feel that any consideration of privacy need have stopped staff from telling others so. I felt that the period spent in the unit belonged to a common experience so that each child's ups and downs ceased to be private. I think, upsetting as it was, that I found it more difficult feeling that I ought to ask about the empty bed-space.'

Feeling for the child

'One thing I found irrationally upsetting. A line tissued leaving what looked as if it would be an abcess in her hand. Similar, but slighter, injuries had happened before. I found it intensely dispiriting for reasons I can't quite fathom. Partly, I think, because it vividly illustrates the perils of intensive care, and stressed (as I knew) that unless she got better, she would get worse. Stability in those circumstances was not enough. It brought home also the idea of decay. And it represented something which would not be all right eventually, as we hoped her major defects would be. This was unavoidable and there was over-reaction in me. I do not know if I could have been helped - I doubt if I could because relatively the worry seemed so silly.'

'Our son's hands and legs were tied for the night to stop him pulling out tubes and scratching his nose which was very sore because of allergy to the plaster. We were very hurt when we discovered this and requested that it should never happen again.'

'There was a lot of difficult times towards the end but the most difficult for us was rushing into her room just before she died and seeing her little face all taped over. It was done as a test on her lungs. It was explained to us though and all the tapes and needles and drips were quickly removed so that I could cuddle her in my arms as she died.'

'The thing that springs to mind was walking in and seeing his eyes taped down, even though this was explained to me after I got a bit hysterical and still wanted the tape off.'

'Seeing him next to the mortuary was very upsetting.'

Accommodation

'Just when our son was having a bad time I was asked to leave the hospital accommodation. We found this disturbing as we are from Ireland and know no one in London and we had been told before we came that we could stay at the hospital. I had to stay in bed & breakfast although there was an empty room below the room my wife was in.'

'The night our baby died, they told my husband there was no room for him to stay which was upsetting. At 5.00 in the morning when he was told our son was dead he had to come right across London. We think more family rooms should be available.'

'It was difficult staying in a top bunk 2 days postnatally. When the ICU drinks machine is not working it is a long way to walk to find a drink.'

'It is very expensive and difficult for families to visit. Could voluntary organisations help and people living near the hospital? If families even brought their own sleeping bags they could have a room at minimal cost and therefore enable brothers and sisters who live very far away to see the patients.'

3. WHAT INFORMATION HELPED YOU?

Most parents said they were very grateful for the information and that it was given willingly.

'Although the junior doctors seemed to know little about her rare illness, The consultant told us all the facts in a caring, direct manner, it was a relief, no matter how painful, to know what was happening.'

'A lady registrar and sister came in and drew a diagram. Also if we wanted to know anything we only had to ask the nurses and they would explain anything at all and put themselves out to help in any way they could.'

'The leaflets about the heart defects helped very much.'

'Throughout, the doctors were willing to talk frankly and intelligently about her condition. Being able to view it at one level in that less emotional way helped.'

'Actually talking to the consultant in a straight forward manner. The sister was very helpful, she organised a telephone call to my husband and managed to get a rule bent so that he could stay overnight.'

'I think this was handled well when she was so seriously ill. We were encouraged as much as we decently could be but we were not left under any misapprehensions. We had the advantage of being there a long time and knowing the staff and they knew us. Telling people you have only just met something which matters so much to them is rather different.'

'We were glad to be able to talk with the doctors and nurses. Even when our son had been dead an hour or two the busy doctor gave us time to think of any questions we had and he did not rush us in things he had to say about a postmortem, etc.'

'Everything was explained fully. If I asked about his drugs I was answered simply, not talked down to. It was just that we had to wait four months for his death to be explained.'

One mother could remember no helpful information.

4. WAS THERE ANY INFORMATION YOU WERE NOT GIVEN BUT WHICH YOU WOULD HAVE FOUND HELPFUL?

'No one volunteered information about arranging to take my wife over from the maternity hospital and by the time she came it was too late.'

'I paid out considerable parking fees before I found I could obtain a ticket or park in the hospital grounds at weekends.'

'Another mother, on seeing I was upset because my daughter did not want to be alone, told me I could stay with her until she had had the

anaesthetic. This meant I was able to keep an important promise, and if my child had died during the operation, as far as she knew I would have been with her. When I asked, the staff said it was fine, but I have the feeling if I hadn't asked I would not have been told.

'We would like to know how many operations of the same type are performed and the success rate, what sort of life our daughter could have expected if she had lived and what further treatment. Only general information was offered to us and we did not like to ask for more as we felt it might be thought to be irrelevant due to her death.'

'We would like to have been fully informed of our son's condition as every doctor was telling us something different. No one offered us advice about funeral arrangements or how to get our son home. Relations had to come over from our home in Ireland to help us to do all this.'

One mother wanted more information but did not say what about, suggesting that this is a difficult question to be certain how to answer.

5. IF YOU WERE ABLE TO BE AT THE HOSPITAL, HOW MUCH DID YOU FEEL INVOLVED IN CARING FOR YOUR CHILD? WOULD YOU LIKE TO HAVE DONE MORE OR LESS?

Most parents were grateful to have felt closely involved in their child's care and that 'the nurses did not mind at all'. Parents of very young babies felt able to give less care.

'I felt very much part of his nursing, allowed to bathe his eyes, wash his face, very simple things but contact is all that matters to a mother, especially if you cannot cuddle the child.'

'I fed him and held him as much as I could. We sat with him all the time except for going to sleep.'

'We were encouraged to care for her and the staff appeared to know how much parents wanted to be involved and helped or left alone (though on hand if required) as necessary.'

'It was nice to be involved and the easy-going attitude in the ward helped to lessen the tension.'

'There was not much we could do for her. We did not feel excluded, save by her condition.'

'My wife and I both found it easier to cope by being together, but I had to go back to work. After a while we both found that 2 visits of 2 or 3 hours was as much as we felt able to cope with in any one day.'

'We were allowed to do a lot for her before and after she died and we cuddled her for a long time afterwards.'

I felt very involved in ICU, even if the staff didn't want me there they always gave the impression they didn't mind, unlike the normal wards, not from all but from some nurses you get the feeling, "Oh another fussy mother." When she got very ill I soon learnt to ignore it and put it down to inexperience of some staff.'

'There was very little I could do, but I could sit by the cot and touch our baby.'

'During her long stay, being able to be there even for an hour each day after work mattered a lot. There was something more reassuring about seeing her. There was always a worry that you might not be able to get in. Our impression was that parents were more readily allowed in during our second stay than during the first time two years previously. We welcomed this. The intercom is an ordeal. The problem is not easy. Obviously people mustn't just walk in. The device is the focus of all the anxiety you

feel when you arrive about how you will find your child, so we are bound to hate it. But all that aside, it is quite difficult to hear the message. When you ring and there is no answer, you cannot tell if has simply gone unheard (more likely) or if everyone inside is busy. If it's the second, the last thing you want to do is exasperate by ringing again, but you worry why they're busy. If it's the first, you wait wondering until you feel you can decently ring again. I think there must be some technical solution. A handset instead of a wall mounted transducer, perhaps, with an automatic repeat of the bell inside (with override!) or some automatic signalling if there's no one in the office to answer.'

6. IF YOUR CHILD WAS OLD ENOUGH TO BE AWARE, HOW DID HE OR SHE FEEL ABOUT DYING? AND IF YOU HAVE OLDER CHILDREN HOW DID THEY FEEL?

'Our 13 year old son did not know what was happening to him as he was kept drugged and so he was very frightened. On the last day, we felt our son knew he was going to leave us and he was very calm and peaceful. He could not speak to us because of the life support machine.'

'Our child was not old enough to be aware, although my wife once said that he knew. Our relative's children were told that he had gone on holiday - but they knew different.'

'She knew she was not getting better and had begun to mistrust and fear doctors. At 4 years she was far too young to go into great discussions on life and death. I just tried to keep things simple like if you are feeling better by - , and perhaps the next medicine will be better.'

'At times we felt she understood quite a lot. Her physical handicaps made it difficult for her to express the full range of her perceptions and this was aggravated by the intensive care. She was heavily sedated for most of her last 10 days. We were very pleased, 2 days before she died, that she had picked up enough to be left awake. Afterwards it seemed very important to me that we had had some communion with her not long before she died.'

'He was so deep in a coma that he didn't know he was dying but his two brothers were very stunned to start with. His two year old sister was too young to understand but she is always talking about him now and the boys have adjusted, they remember more happy times than pain. I told them honestly that he might die.'

'We only told our children a little that their brother was not well. I think perhaps we should have given them some warning, because they had an awful shock when they were told he had died. The nine year old said he did not believe it was true and he had a particularly hard time getting over his brother's death. He thought it was babyish to cry and the tension of his grief was not relieved.'

'The older three were very upset and kept asking why.'

'Our 5 year old was very upset because she had so much looked forward to the baby's arrival and was sad she did not see her baby after months of waiting.'

'Two years later we and our two sons are still trying to cope with it.'

'My children still feel sad but they accept her death. I think help for them would be in trying to cope with my swings in mood and how to accept that I will never be the same person as before. But we do talk openly about her and I think it helps them and perhaps me as well.'

'He was our only child.'

7. HOW DID YOU FEEL ABOUT THE EMOTIONAL SUPPORT FROM THE DOCTORS, NURSES, SOCIAL WORKERS, CHAPLAIN OR OTHER STAFF?

'The emotional support from everyone was fantastic, especially the nurse who looked after him the night he died and was with us when we were told. She took us through to see and hold him, and knew when we wanted to be left alone or needed her support. We cannot praise the nurses enough, we know they did everything possible.'

'The PICU nurses were very compassionate and the nurses on Rose were genuinely upset at our daughter's death.'

'The sister in charge showed sympathy along with being fully in charge of the situation. This gave us strength. She told us firmly things we needed to know and things we had to do. The frequent offers of cups of tea were appreciated! We were glad of the chaplain's prayers and concern.'

'ALL the staff were marvellous.'

'We could not have received better help from the doctors and nurses and by enclosing this cheque we hope this can help.'

'They were all wonderful, but I would have treasured a talk with the surgeon.'

'One nurse especially helped a great deal while I was waiting for my daughter to die and for my husband to arrive. She had been nursing her on other shifts and I felt I knew her. I think when your child is that ill perhaps the fewer different nurses they have the better because it doesn't seem so impersonal when the nurse you know comes back on duty and you feel she understands what your child has been going through.'

'I'm not sure what time she really died. I know she was dead before the machines were turned off but from about 3am the two of us sat in a little room in ICU obviously used for bereaved parents. We didn't see anyone until the morning. I was completely drained of any real emotion. I knew she was going to die but still felt completely shocked that this time she really had. About 7.30 I had to leave that awful room so I went to get some coffee from a machine. Then a nurse saw one of the parents asking me how my daughter was and she found a doctor to make out the death certificate and that was it. We could have done with more help the morning afterwards, perhaps from the chaplain. I didn't even want to go home. I left most of her things except her teddies, then we trudged to Chelsea Registry Office. In the end we couldn't get a taxi so we got a tube to Paddington. We had to stand all the way home on a 200 mile train journey because it was the day before bank holiday weekend.'

[This example shows the difficulty for parents of entering PICU when their child is no longer there. The intercom is used for requesting access to the child, not for parents to ask for help on their own behalf. It is also difficult for staff to contact parents or to leave messages for them after the child has died or while a child is in theatre because there is nowhere comfortable in the hospital where waiting parents are likely to be found. A third difficulty is for parents to have to make decisions, often alone and in a hurry, such as which of their child's possessions to keep, knowing that whatever is left will be destroyed. It would help if a nurse or special volunteer were available to parents, and helped them to pack, offering to keep the child's possessions for a while in case parents change their mind about what they wish to keep.]

'I think it helps to talk to doctors although I felt nothing but rage and anger even hatred for the doctors at our local hospital. I am prepared to accept they did the best they could but I think they were wrong in not

telling us about the illness and the problems. They probably thought they were protecting us from worrying but I would not accept what they said, I read as much as I could and soon realised that her condition was a terminal one.'

'We felt we received very little emotional support, if any, from the staff. We felt when our son died no one wanted to know us anymore. It was as if all the hospital's responsibility was over. We think you need to look at the support given to overseas visitors and especially when their child dies at the hospital.'

'I'm afraid we had no support.'

8. DID OTHER PATIENTS AND PARENTS HELP YOU, AND IF SO HOW?

'Just talking.'

'A lot of sympathy and encouragement from other mums, they didn't need to say they knew they were lucky and it could have happened to them.'

'Other parents understood our feelings and gave us emotional support.'

'It was nice talking to another couple and knowing it was not only us going through it all. We often wonder what happened to their baby.'

'We listened to, and had the help and support of other parents who had suffered and lost their love-ones.'

'Other parents showed their concern when he died and once when I had bad news about him a mother let me talk and cry it out with her.'

'The parents know the type of hell you are going through and have gone through, endless hours of waiting in outpatients, xray, admissions, pharmacy, sleepless nights and FEAR. We got to know another little girl and her family well and when you are feeling down and far away from home it is just nice to see a face you know.'

Several parents did not answer this question.

9. HOW CAN PARENTS AND OTHER RELATIVES BE HELPED AFTERWARDS, SUCH AS BY COMING BACK HERE AND TALKING TO SOME OF THE PEOPLE WHO CARED FOR YOUR CHILD, OR BY TALKING TO YOUR G.P., PAEDIATRICIAN, HEALTH VISITOR OR MINISTER OF RELIGION?

'We feel there is no straight answer. Individuals react differently and have to be treated accordingly.'

'There are no rules or laid out ways of dealing with this sort of tragedy. My husband has left us and we have not heard anything of him for months. Myself and the children are building a new life and are very happy but we still cry for her.'

'Help is limited by what it can achieve. In the end it is the parents themselves who must come to terms with the situation, support each other, put their lives in order and carry on with life, however difficult it may seem at the time.'

'It would be nice to go back and see the people who looked after him. It was a help talking to our GP and most of all to family and friends who listened to our ramblings.'

'Afterwards there was a big hole in our lives, not just emotional but practical too, because we were no longer visiting the hospital. We think it might have helped if we had someone not formerly involved to talk to before she died. This was the benefit of talking to Dr Culliford. I'm sure there were people there but it didn't really occur to me to ask. Going back is painful but perhaps it ought to be obligatory.'

'There is nowhere in the world I want to go to less.'

'I don't think returning to the hospital would help. It would bring back painful memories. My health visitor was helpful and I felt at ease with her, but she never came back, I think she left. Our minister and our christian friends help. It was and still is good to know of someone whose shoulder I can cry on.'

'We had help only after seeking it from our local minister.'

'We came back to see Dr Shinebourne afterwards and although we were very upset he told us all we wanted to know and was very kind and sympathetic. We were very lucky to have good support and love and care from our priest and our family and good friends. My doctors at home are not so helpful as those at the Brompton. We all get great comfort from being able to talk about her and look at pictures of her.'

10. WOULD IT HELP TO HAVE MORE INFORMATION ABOUT HOW TO HELP YOUR OTHER CHILDREN OR HOW YOU MAY FEEL IN THE WEEKS AND MONTHS AFTERWARDS?

Many parents wanted more information and said they would like to have had a booklet, and that if one were produced they would like to be sent a copy..

'I would like to see a booklet about people's reactions and the stages you go through although bereavement is a difficult subject. Also help with explaining to the other children. I found the organisation called SANDS was very helpful and a book called "To live again" by Catherine Marshall.

'We have coped. But some people are not strong enough emotionally and any information they get would be helpful.'

'We just feel numb.' 'I don't think people can tell you how you are going to feel, everyone feels and thinks differently.'

'My husband doesn't feel we would benefit from any information whereas I think it could help parents to feel less alone. I found it comforting to read a book about mothers with feelings of loss and misunderstandings by other people when their baby died which were similar to my feelings.'

'If I was confronted with a bereaved parent I couldn't possibly say, "I know how you feel". My feelings and the reaction of another parent could be completely different and their particular hell be nothing like mine. I only know what it did and is doing to me. The ICU nurse, Melanie said the most sensible thing, "It's going to be very hard", and she was very astute and correct, in fact, the most helpful person at the hospital. Anger, rage, resignation, depression, wanting to kill yourself, self-pity, and nightmares about the pain inflicted on your child trying to save her life, they go through your mind very often. Grief is a very personal thing, IT IS A LIVING HELL. I wonder if something can be done in a form of counselling, though how you counsel the unknown I'm not sure.'

'In our son's case we were both resigned to his death when it finally came. In some ways I at least felt that he no longer had to suffer. This made it easier in the long term to accept and come to terms with.'

'I would like to know more about how to help my other children. Often I found they were not themselves only to discover they too felt the loss of their brother. Also to have information about feelings in the months afterwards would be useful. One minute you can be feeling back to normal and the next moment the sense of loss floods into your life again.'

'I was helped by reading a book by Doris Stokes, by talking with so many other people who have suffered. Painful memories but time is the only healer and being able to talk about the events; happy memories, because of memories we have moved houses.'

11. HAVE WE LEFT OUT ANYTHING IMPORTANT WHICH YOU THINK WE NEED TO LOOK AT?

'It would be helpful if a nurse or social worker who knows the parents well enough accompanies them to the administration office in the hospital, and to the coroner's office and the town hall. London is a big city.'

'I am filling in this form for my daughter. THE WORST PART was GETTING THE DEATH CERTIFICATE and SEEING THE REGISTRAR who was very uncaring. My daughter was very upset and the man was no help.'

'Our son died late on a Friday afternoon. Sister told us we would need to register the death at the Chelsea Office which closed at 4pm. When we returned to the hospital on Monday to complete the registration we were told a postmortem would be necessary. We felt the trip from Essex was a waste of time and we returned to London on Wednesday to complete the practicalities. We would have thought the Sister could have explained about the postmortem before we made the journey.'

'He died on a Saturday and sister asked us to come back next day to sort out the details. On Sunday there was no one around to help and we had to return again on Monday.'

'We had to return to the hospital after the weekend to collect the certificate. It would have been useful if we had been told that we needed to bring her medical card to register her death. As it was we had to make a visit to the district once to collect papers and once to register. Perhaps a leaflet in PICU would be a good idea.'

'It was good to be advised on sorting out registering his death while we were still at the hospital. It would have been difficult to go back there again.'

12. WOULD YOU LIKE TO COME TO A MEETING AT THE BROMPTON HOSPITAL ABOUT THE CARE GIVEN TO FAMILIES WHEN A CHILD DIES HERE?

7 parents said they would like to attend a meeting,
5 parents said thank you, but no,
6 parents did not give a definite answer.

'It would still be very painful for us to attend a meeting but I would try and make the effort. After all my child had to attend there so many times in her short lived life. It will soon be two years ago. She was such a brave little girl I feel for her sake I would try my hardest and attend the meeting.' (This mother had given a 'no' answer to questions without explaining her difficulties, suggesting that for many parents it is easier to talk, than to write down answers.)

'I feel unable at present to return to the Brompton after the very sad loss of our child, but if you would like to contact me by phone I would be delighted to talk to you.'

'This meeting should be for people who are emotionally weak. We can cope.'

THE NURSES' VIEWS

Questions about nursing care when a child dies are not very suitable for the medium of a questionnaire. The comments are in some ways more informative than the tables. Many items were left unanswered and therefore show a low score, which seems more likely to indicate uncertainty than satisfaction.

1. WHEN A CHILD IS DYING OR HAS DIED, WHAT DO YOU TEND TO DO WITH HIS/HER PARENTS?

(total number of ticks)

a) try to leave them alone	19
b) try to talk about ordinary or cheerful things	3
c) encourage them to talk about their sadness	37
d) just sit with them quietly	38
e) if you feel upset, share your distress with them	34
f) encourage them to cry	26
g) touch them comfortingly	48
h) talk about practical arrangements	24

Comments: 'It varies so much. Some like to be left alone to grieve, others need comfort and the chance to talk.' 'You have to find out what they want.'

'Depends entirely on the nurse's relationship with the parents, the nurse's own emotional *status quo* and the amount of time available.'

'At some stage they usually like to be left alone to say things privately.' 'Always ask if they would like to be alone with their child and I will be just outside, always offer for them to cuddle their child.' 'It is often difficult for them to talk at such an early stage of grief.' 'Make them a cup of tea and allow them quietness and to open their hearts if they so wish.'

'It's worse when a child dies in theatre and we have to deal with the parents in PICU when we do not know them. It would be better if a nurse from Rose who has known the child and the parents before helps in comforting the parents.' A nurse in Rose thought that too little of her time was spent involved 'with parents you know well, immediately after the death of their child'.

2. WOULD YOU LIKE TO SHOW MORE SYMPATHY?

37	nurses said yes
16	nurses said no
5	nurses gave no answer

26 nurses held back from showing sympathy because they were not sure how to help

21 were worried that they might upset the family

1 nurse felt unsure about what other nurses would think of her behaviour.

Comments: 'I try to show sympathy by just sitting with them, if other duties permit, and by writing to them.' 'We learn each day to show more sympathy. Some nurses are naturally gifted, some need to learn and are

unsure how to help. This can be uncomfortable, and support and counselling is needed for the nurses.' 'It might help if we all had some help in caring for dying patients and bereaved parents, the skills are not just learnt by experience I believe.'

On sharing distress: 'I feel that it's important to say to them that you share their grief but not to break down (although very difficult) as I am there to remain strong to support them, also to maintain silence at intervals.' 'Normal human emotion is in my experience a comfort to parents as long as it is "controlled".' 'I show feeling especially if I have become close to the parents.' 'I have often cried with parents.' 'It is very difficult because people have different views about expressing grief.'

3. DIFFICULTIES WHEN AN OLDER CHILD IS DYING

- 16 nurses felt not sure how to help
- 17 nurses worried that they might upset him/her
- 1 nurse was not sure what other nurses would think of her behaviour
- 20 nurses felt guilty or had a sense of failure

Comments: 'I feel helpless.' 'Sad because they are so brave and a huge sense of loss. Often think of them and their parents for a long time afterwards.' 'I feel desperate for the parents.' 'It's a blessing for the child not to have to suffer anymore.'

'You must be honest with children because they know what is going on.' 'Depends on the child's knowledge and personality.' 'I am personally very frightened of dying and find it hard to "cope" with the older child dying because of my fears.' 'If they are awake and aware I try to be "brave" for them when I am with them.'

4. DO YOU THINK THERE ARE ENOUGH FACILITIES AND HELP FOR PARENTS WHOSE CHILD HAS DIED?

	enough is offered	more should be arranged	don't know
a) a quiet private place	23	31	4
b) someone to sit with them	17	33	8
c) help with finding friends/relatives	32	16	10
d) practical help	26	20	12
e) financial help	15	19	24

Comments: A nurse's time is not always available.' 'Not always easy to find anywhere quiet for them to sit.' 'We need a good chapel of rest.' 'Overall, I feel we have a compassionate team willing to help in any area with parents' problems.'

Some nurses were concerned about follow up care. 'Some kind of continuity with the unit should be arranged for parents. I feel we abandon them once the child is dead, having supported them for so long and established good relationships, I think this might help the nurses' grieving too.'

'Follow up opportunities seem a bit haphazard at times. I'm not sure if all parents are encouraged to come back to discuss things afterwards.'

'Is genetic counselling offered?'

'We should involve organisations more, such as Parents' Lifeline.'

Many nurses said they did not know about practical and financial help.

SUGGESTIONS

1. All the hospital staff and especially the nurses should be confirmed and supported in the care and kindness they show towards dying children and their families.

Help for nurses

Nurses say they need:

- a) more time to attend to the families;
- b) more knowledge, discussion and training about giving terminal care;
- c) more help, support and counselling while they are giving this care;
- d) improved facilities for parents.

2. As suggested in the Nursing Satisfaction Study Report, if more nurses were employed, the burden of work and stress would be eased and it would be easier to put other suggestions into practice.

3. A fulltime nurse counsellor could arrange a course in the care of the dying child, researching the experiences of nurses and patients, evaluating practice, and while supporting nurses in their work, helping them to channel their reactions and ideas into practical ways of reducing avoidable distress. Résumés of meetings could be given to all nurses. Changes in care could then be evaluated.

4. Counselling and teaching sessions could perhaps cover:

- discussion among nurses about practices which they have found helpful or difficult so that fuller use is made of the knowledge and experience among the staff;
- ways of confirming good practice instead of leaving nurses uncertain about whether their work is beneficial;
- ways of responding to hidden requests for help from children and parents;
- the changing understanding of children at different stages of illness and of maturity, with practical ideas on communicating with them;
- means of helping families and staff to cope with terminal care and bereavement;
- means of adapting hospice forms of care to acute, intensive care when death is often sudden and unexpected;
- inviting bereaved parents to return to talk to small groups of nurses about which practices they found helpful.

5. Research on stress suggests that hospital staff prefer counselling support from someone who shares and understands the work of the unit rather than someone from outside the unit. However, some parents and possibly some nurses wanted to talk to someone who was not involved. It may be useful to have a nurse counsellor and a social worker involved in the daily work of the unit with links with a visiting psychologist, psychotherapist or psychiatrist.

Helping children and parents during the child's illness

6. More knowledge is needed about talking to sick children and to their brothers and sisters about terminal illness. A small library of books,

pictures and story tapes could be made to help nurses and parents in talking and listening to children.

7. While their child is very ill, parents could be considerably helped if: they had free accommodation as is given in many other hospitals; the option of one parent staying in a cubicle with the child was considered;

there was more understanding of parents' need to stay together and more double and family accommodation;

postnatal mothers could be transferred more promptly from the maternity hospitals and could have comfortable accommodation and meals provided nearer PICU;

the PICU intercom could be a telephone which rings until answered and through which voices are clearly audible and a system could be arranged so that waiting parents are not forgotten;

hospital administrators could take on more responsibility for informing parents about car parking and fares help;

siblings and other relatives of very ill children could be encouraged to visit in PICU;

parents' meetings could be arranged on ROSE and PICU to encourage parents in supporting one another;

a quiet place for parents to sit could be found in Rose Gallery, like the new room in PICU;

all parents could be informed about the opportunity to go to the anaesthetic room with their child;

doctors could talk to parents when their child is delayed in theatre for a long time.

8. More knowledge is needed about families' wishes concerning how and where their child dies. For example, doctors sometimes advocate extremely risky surgery as a compassionate form of release. This may not accord with the wishes of the parents and the child.

Helping parents after their child has died

9. A list could be made of all administrative arrangements parents must carry out after the child's death. The timing could be arranged with the parents and they could keep a copy of the list to save unnecessary journeys. A nurse could be assigned to help parents to carry out arrangements connected with the hospital.

10. In some hospitals a nurse is assigned to stay with parents, or to be available to them, after their child has died until they leave the hospital, helping them with arrangements such as packing, registration, transport home, financial and follow up information, which they may feel too shocked to manage on their own.

11. When parents know nurses in Rose gallery but not in PICU, a nurse from Rose Gallery could be assigned to stay with them.

12. Because nurses and social workers often do not have time to help parents after the child's death, an experienced volunteer could be appointed to help parents in the hospital and perhaps go to the Registrar's Office with them.

13. Parents appreciate being able to talk with a surgeon if their child has died in theatre.

14. A good chapel of rest is needed and a children's book of remembrance could be placed in the hospital chapel. Parents could choose whatever they wish to be inscribed on their child's page.

16. A short book could be written to help bereaved parents and to supplement the support they receive from the staff.

17. When a report is sent to the child's GP, a leaflet could be enclosed about the particular problems for parents whose child dies in a supra-regional referral centre suggesting sources of help. The GP could use the leaflet or pass it on to the parents. The leaflet could be compiled at the Brompton Hospital, based on the experiences of parents.

18. Letters are usually sent to the parents from the consultants, social worker and/or nursing staff. In one of these letters, parents could be asked if they would like to be put in touch with other bereaved parents from the hospital to telephone or write to them. A small register could be made.

19. When parents are invited to return to talk to a consultant they could also be asked if they would like to talk with one of the nurses who helped to care for their child, and also to the social worker or the special volunteer. If this could be arranged, nurses who are concerned about 'suddenly abandoning bereaved families' might benefit, as well as the parents.

20. Non-English speaking parents We are concerned that we have not considered non-English speaking parents. Perhaps one of the embassies would commission some research into their needs, or a report might be made by one of the nurses who can speak another European or Asian language.

21. Further information Parents of children who die at the hospital at sometime over the next year could be asked for their views next summer in a letter which allows a longer time for answering.

In summary The parents' reactions could be grouped into four kinds:
* some found a great deal of help from the staff and other parents;
* some were distressed about specific difficulties;
* some felt they were not given help, or for some reason they could not accept help - it is difficult to tell how much their criticism was caused by unhappy experiences or by their response to the staff or both;
* most parents did not reply to the letter.

Some parents will support these suggestions as helping to ease their distress during their child's illness and in the difficult following months. We acknowledge that other parents may think some of these suggestions make an unnecessary intrusion. We need to know more about the immediate and long term effects of the care being given in the hospital.

APPENDIX 1

Nursing satisfaction study

Questionnaires were personally distributed to 74 paediatric nurses at the Brompton Hospital during August and September 1986. Most of the questions were about work satisfaction, conditions and expectations. The direct answers were analysed on the hospital computer minitab system. Nurses also added many comments which have been used in the reports.

Copies of the full report are available from Bridget Comer.

APPENDIX 2.

Note on the administration of the parents' study.

The letter to parents (page 19) went through several drafts during well over a year of discussions and meetings. It was finally approved by the Hospital Ethics Committee.

A stamped addressed envelope was enclosed, for parents to return their answers. The questions were printed on green paper and were sent inside the enclosed envelope, so that after reading the letter of request, if they did not want to reply, parents could avoid reading the questions. In this way we hoped to reach a compromise between parents being distressed at receiving the questions without any preparation, and writing twice to them, the first time to ask for permission to send the questions. It was felt that the latter approach would seriously reduce the response rate, and that the main cause of possible distress was likely to be the actual request for information rather than the wording of the questions.

Replies were received over six weeks during August and September. Apart from the subject matter, reasons for the low return rate from parents may be that:

- no reminders were sent;

- the letter mentioned a meeting 'in the summer' but it took so many months to reach agreement over the letter that it was not sent until late July. Parents who replied within three or four weeks hoped that they were 'not too late'. It would probably have been preferable to change the phrase about the summer and also to assure parents that there was no urgency;

- the letter was sent at the beginning of the school holidays; several parents said that this was a difficult time to collect their thoughts;

- the letter mentioned possibly using the replies for a booklet to help other parents. Although this may have encouraged some to write, others might have answered a more private survey;

- a high proportion of bereaved families move house, and may not receive letters to an old address.

SOCIAL SERVICE DEPARTMENT
BROMPTON HOSPITAL
FULHAM ROAD
LONDON SW3 6HP

TELEPHONE 01-352 8121

Dear

I am one of the Social Workers here and I am writing to all parents whose child has died at the Brompton Hospital recently. We are taking a critical look at the care we provide for parents of a child under these circumstances. One of our aims is to write a booklet for parents, with helpful advice and information and we would like you to help us write this.

Please answer the enclosed questions if you feel like it. We would be grateful. A stamped, addressed envelope is enclosed. I hope that you will not mind my writing to you about this and of course I do understand that you may prefer not to reply.

In the summer we are thinking of having a meeting here with a small number of hospital staff if parents answering our questionnaire feel this would be of value.

Thank you.

Yours sincerely,

Sue Rees (Mrs)
SOCIAL WORKER

Questions for parents whose child has died at the Brompton Hospital

We would be grateful if you would let us know your views on the help and support given to the family when your child died at the hospital. Thank you very much for your help. Please return this to Mrs Sue Rees in the enclosed envelope.

Was there anything especially comforting which happened at this hospital?

Did anything happen which was particularly difficult to cope with, such as something someone said or did, or something you were expected to do?

What information helped you? (For example about your child's condition or care, the practical arrangements, or about ways of coping with difficulties).

Was there information which you were not given but which you would have found helpful?

If you were able to be at the hospital, how much did you feel involved in caring for your child? Would you like to have done more or less?

If your child was old enough to be aware, how did he or she feel about dying and, if you have other children, how did they feel?

How did you feel about emotional support from the staff such as from doctors, nurses, social workers, hospital chaplain and other staff?

Did other patients and parents help you and if so how?

How can parents, relatives and other children be helped afterwards such as by coming back here and talking to some of the people who cared for your child, or by talking to your G.P., paediatrician, health visitor or minister of religion?

Would it help to have more information about:

How to help your other children?

How you may feel in the weeks and months afterwards?

Have we left out anything important which you think we need to look at?

Would you like to come to a meeting at the Brompton Hospital about the care given to families when a child dies here?

WHAT THE PARENTS THINK

A survey in two paediatric cardiology units of the views of parents about the information and facilities provided for families by the units.

415 questionnaires were distributed to parents in two London paediatric cardiology units over 14 months. The intention was to discover the parents' views about the information they received before and during their child's admission for surgery. Parents were also asked about how much they felt involved in caring for their child in hospital and their opinion of the facilities provided for child patients, for parents and for visiting children.

Survey method

1. Preparation Parents, medical and nursing staff, social workers and play workers were interviewed in the two units in order to discover the aspects of information and family facilities which they considered to be the most important. A questionnaire was devised based on their responses.

The questionnaire was also based on research into parental involvement in children's nursing, (1,2) and with adult patients (3). Thompson aimed to obtain 'hard' data from the 'soft' subject matter of patients' subjective experiences and levels of satisfaction. He asked patients to fill in an attractively designed booklet which offered a choice of responses to many questions, ranging from very satisfied, through moderately pleased, to dissatisfied. The replies fall broadly into categories of satisfaction which, when based on sufficient numbers of patients, can be useful to health service managers as performance indicators.

A draft questionnaire was used as a pilot with 20 families and was revised twice following comments from parents and hospital staff. The questionnaire was approved by staff in both hospitals and by a research ethics committee.

2. Distribution Questionnaires were distributed over 14 months from January 1985. They were given to parents after their child's heart operation, as far as possible when the child no longer needed intensive care. The sample excluded parents:

- * of non-surgical patients;
- * of children admitted in an emergency;
- * who did not speak English:

-
- 1) N. Blake Research on parental involvement in the paediatric unit, Queen's Medical Centre, Nottingham, 1984
 - 2) Nurse, I want my mummy! P Hawthorne, Royal College of Nursing 1976.
 - 3) A.Thompson What the patient thinks, unpublished PhD thesis, University of Manchester Institute of Science and Technology 1983

- * whose child was discharged from intensive care immediately back to the referring hospital;
- * who had already had a questionnaire after their child's previous surgery;
- * whose child was having serious difficulties after surgery;
- * who were thought by nurses to be too distressed to be asked to fill in the questionnaire.

Usually, parents did not receive a questionnaire if the days between their child's intensive care and discharge did not coincide with my visits to the units.

Attempts to cover all the children admitted for heart surgery, such as nurses giving a questionnaire at admission to each family, and asking parents to complete it a few days after the operation produced a very low return rate.

I left a questionnaire at the child's bedside when parents were absent from the ward or did not have time to talk, but when possible I spent about 10 minutes (this often developed into a much longer time), talking with parents about the survey and filling in the page of personal details with them. The purpose was to obtain more complete replies to these questions and also to see whether a personal or an anonymous approach elicited a higher return rate.

On the cover of the questionnaire was a letter asking the parents for their help and saying: 'There are no right or wrong answers to most of the questions, it is just your views that matter. This survey is not about the medical treatment. It is to help the hospital staff to see where the non-medical side of care is going well, or where it might be improved in order to help other families... Your replies are anonymous and will be kept confidential.' The parents were also told that the survey was being carried out through London University and their replies would not be seen by the hospital staff.

The parents were asked to add their own comments. They were given an envelope in which to leave the completed questionnaire with the ward clerk or in a filing tray on the ward. They were not reminded about returning the questionnaires, in order to avoid putting pressure on a relatively stressed and captive group.

Results

<u>1. Return rates</u>	<u>in Unit 1</u>	<u>in Unit 2</u>	<u>Total</u>
The number of questionnaires distributed:	230	+	185 = 415
The number of adequately completed questionnaires:	161	+	117 = 278
<u>Percentage return rate:</u>	70%		63% <u>average</u> 66.5%
Return rate of questionnaires given without discussion:	51.4%		35.4% 46.4%
These were distributed during a period with a lower overall return rate, the response for questionnaires given with discussions being:	69.6%		67.7% 68.6%

2. Personal information

a) Age The children's ages ranged from under one month to 16 years. The mean age was 42.6 months and the median age was 24 months.

b) Out-patient clinics 1 Between them, 271 of the children had attended an estimated total of 959 out-patient cardiac clinics at the London units. The maximum attendance was estimated by parents to be about 50, the minimum was none, the mean attendance was 3.5, and the median 1.

(271:7)§

c) Out-patient clinics 2 273 of the children had attended an estimated total of 1992 cardiac out-patient clinics at hospitals other than the two London units, usually the hospital which could provide this service nearest to the child's home. The estimated maximum attendance was 200 clinics, the minimum was 0, the mean 7.30 and the median 3. 'Cardiac clinics' were defined as an out-patient appointment with a hospital doctor primarily in order to consider the child's heart condition. The doctor was usually a local paediatrician, cardiologist or paediatric cardiologist, or else a paediatric cardiologist from one of the London units who visited the local hospital in order to hold a joint cardiac clinic with the child's general paediatrician.

Parents commented on the benefits of local clinics which saved them long journeys and much expense and anxiety. They appreciated meeting a London paediatric cardiologist before their child's admission as he was often able to tell them more details than their local doctors could give. The disadvantage of joint clinics was that families sometimes did not visit the London hospital before the admission and they felt that they missed some useful pre-admission experience.

(273:5)

d) Admissions 1 275 of the children shared a total of 637 admissions to the two units, 'for the heart condition, not for other problems'. There was a minimum of one admission, a maximum of 13, and a mean of 2.3 admissions.

(275:3)

e) Admissions 2 273 of the children shared a total of 357 admissions to hospitals other than the two units. The minimum was 0, the maximum 30 and the mean 1.3 admissions. Parents were asked to include only admissions 'for the heart condition, not for other problems'. This was often difficult to define. Children were admitted for problems such as 'chestiness' which parents considered were related to, sometimes caused or exacerbated by the heart condition. The parents felt that the child would not have been so ill or would not have been admitted as a precaution if the heart were normal.

§ Figures in brackets at the end of a section denote the total number of replies and of non-replies. Where totals do not tally with totals for sub-sections of a question, too many answers mean that parents have ticked more than one answer, too few answers for a total mean that comments which do not fit the given categories have been included as answers.

The main purpose of this question was to measure the in-patient experience and opportunity to gain information for each family, during times when the child's heart condition was a central concern.
(273:5)

f) Total number of inpatient weeks in any hospitals primarily for the heart condition. The minimum was less than a week, the maximum was about 3 years, the mean was 7.6, and the median was 3 weeks. 263 of the children shared an estimated total of 2,017 weeks in hospital.
(263:15)

g) Echocardiography Parents' estimations of the number of echoes performed on their child were too vague to be worth analysing. This is not a procedure for which formal parental consent is sought.

h) Cardiac catheterisation 272 of the children shared a total of 401 cardiac catheterisations, with a minimum of none, maximum of 9 and mean of 1.4.
(272:6)

i) Heart surgery 273 of the children shared a total of 416 operations. All had had at least one palliative or corrective cardiac operation, not including procedures performed by catheterisation. Some parents excluded non-bypass cardiac operations from their total; some parents included surgical treatment for problems related to the heart condition such as a plicated diaphragm. Their estimates are therefore open to dispute. However from the parents' point of view, the highest total was a child who had had 12 cardiac and related operations in his first year. The mean number of operations per child was 1.5.
(273:5)

j) Previous experience The numbers of children having:

their first operation with no previous catheterisation were ..	58
their first operation after one or more catheterisations	128
their second or subsequent operation	88

(274:4)

k) Siblings Between them, 275 of the patients had 346 siblings. One child had 14 siblings and the mean number of siblings was 1.2.

126 children were the first or only child in the family, 81 were second, 47 third, 2 were sixth in the family.

Of 275 patients, 142 had siblings aged under five years, 14 had 2 and 7 patients had 3 siblings aged under 5 years.

(275:3)

Parents were asked about their other children, particularly those under five, in order to record some of their other responsibilities and likely anxieties during their child's admission.

During discussions, parents often raised three related issues which they considered important but which the questionnaire did not provide for: the experience with deceased siblings, (some of whom had had heart problems); the extra problems for mothers who were pregnant

during their child's admission; the differing experience of partners with children from previous marriages.

1) Travel Parents from abroad were not asked about travel.

i) The time for the journey from home to hospital varied from 15 minutes to 7 hours. The mean time was 2.02 hours.
(257:21)

ii) The vehicles for transport to the hospital included car, train, bus, underground train, coach, boat, plane and ambulance. Of 256 families, 106 travelled by car and 150 families used public transport for all or part of their journey.
(256:22)

iii) The cost. In order to standardise the answers, parents were asked the total fare for an adult journey from home to hospital and back. The cost of car journeys was calculated at £4.75 per hour, a compromise between the NHS travel allowance and an allowance for 30 mph using £2 worth of petrol. Parents varied between giving full and off-peak costs of public transport. The totals here do not include the costs of fares for two parents and for their children, or the high car parking charges as both hospitals are in parking meter zones. One has recently closed its car park because of new building. These totals therefore do not represent anything approaching the total expenses for many families.

The least expensive return journey for one adult cost £0.60 and the most expensive one cost £180. The mean cost was £15.23 and the median was, £11.88. The shared costs for one adult return journey for 253 families amounted to £3,853.10
(253:25).

One reason for asking these questions was to be able to group families by personal and hospital experiences, to see whether certain groups tend to report higher levels of satisfaction or of anxiety. This first paper just reports the basic data.

The results of the main part of the questionnaire will now be given. Most questions are set out as they were on the questionnaire.

* Questions marked * gave parents the option of answering as few or as many points as they chose. A low return does not necessarily denote high satisfaction. A clearer method would be to ask for a graded answer to each item, for example, giving boxes for 'very much', 'moderately' and 'very little', the method used for questions 6.1-3, 7.1, and 10.4. However, using this method too often made the questionnaire even more complicated to fill in and to analyse.

3 Information before admission

3.1. Nature of medical information

[Total number of ticks
meaning 'yes']

* Before my child came into hospital this time,	
a) I was told as much as I wanted to know about what the doctors knew at that stage	218
or I would like to have known more about:	
b) my child's heart condition	35
c) why the treatment would be given	18
d) what the treatment would involve	34
e) the future outcome for my child	43
f) other (please describe)	10

'Other' included, 'what symptoms to expect if the condition became dangerous', 'how quickly she would recover', 'wanted to know more about after care', 'whether he will in future have any pains or trouble from the area of operation'.

Some parents ticked a) and another answer, acknowledging that doctors were not able to answer their questions until they obtained more information during the child's admission.

3.2 Clarity of medical information

Before my child was admitted this time on the whole the medical information I was given about the topics in question 1:

a) left no shadow of doubt in my mind	137
b) gave a full picture although I would have liked a little more	81
c) gave many details but was too technical and confusing	31
d) did not give many details	14
e) left me very much in the dark (270:8)	7

Comments included, 'we were told very dramatically, nothing was spared', 'I thought I understood clearly but it transpired it was not complete information'. One mother explained the difference between understanding and having time to accept the information. 'When my daughter was first diagnosed with this heart condition, I found it extremely difficult to accept as she appeared very healthy. I could

not understand why this operation was necessary. I think I did not want to accept the truth, and therefore did not want to co-operate with the doctors. I had been through this same operation with my son 10 years ago, and perhaps felt this should not be hapening again. It was not until she was admitted that I learned the whole truth about the seriousness of her condition. It was only then that I fully understood and accepted the facts.'

3.3 Potential further sources of general information

* Before my child was admitted this time,

a) I knew as much as I wanted to about what to expect 189

or I would like to have had more chance to
[have access to further sources of information
summarised here as:

a) talking to the doctors 47

b) seeing round the hospital and/or talking
to nurses, social worker and/or other parents 59
(263:15)

Comments included, 'Find out about accommodation', 'talk to the doctors and social worker for accommodation in the hospital at least for those of us from far countries, that have no relatives here', 'talk about staying with my child'. Parents wrote about the worry of being kept in suspense about whether they could stay. Another question was, 'to know how long he'd be in if all went well so I could organise care for my other children'.

3.4 Most helpful source of preadmission information

(apart from previous admission which many parents ticked, the answers were:)

a) out-patient clinic 38

b) pre-admission visit to this hospital 65

c) a local doctor 87

d) other 57
(243:35)

'Other' included, naming particularly helpful doctors, 'our local hospital', 'letter from the consultant', 'admission book' and 'accommodation officer'. Parents in the second hospital praised the Nursing Officer's book explaining heart surgery and the British Heart Foundation illustrated sheets. The said they would like to have seen the unit's photographic book following a child through surgery before admission. 'You can actually see what your child would look like and be going through. There is still too much left to circumstance and

Many parents said that although they would like b) a preadmission visit, distance from home made it impractical. Formal visits are not arranged, and so the b) answers may often mean a clinic in one of the London units and not at the local hospital.

3.5 Parents' ease in preparing child for admission

When I explained to my child about coming into hospital:

- | | |
|---|----|
| a) I had been given the information I needed | 81 |
| b) it would have been easier if I had been given more information | 20 |
| c) I found it very difficult to answer his/her questions | 9 |

Many parents added that they thought it was unnecessary to prepare children. One parent wrote, 'I wanted advice on what to tell my child, whether to warn him he'd be in pain and have a tube attached, etc., or if he'd forget about it afterwards.'

(115:163)

4.1 Pre-admission anxiety of parents

When my child was due to come into hospital this time:

- | | |
|---|-----|
| a) I was nervous but not too worried | 74 |
| b) I was very worried about what might happen | 120 |
| c) I was expecting the worst | 53 |

Comments included, 'I was not at all worried', and one parent added to c) 'but hoping for the best'.

(249:29)

4.2 Pre-admission anxiety of child

Just before coming into the hospital my child:

- | | |
|---|----|
| a) was looking forward to the admission | 33 |
| b) seemed calm | 54 |
| c) was nervous | 38 |
| d) seemed very worried | 10 |

Some parents ticked b) and c). Comments included, 'not about the operation but about the blood test because of a previous bad experience'. The lowest age at which a child was thought to be anxious was 12 months, 'he seems to feel that things are different'.

(135:143)

Parents added notes about the worry of very short notice about admission, and about cancelled operations. 'My child and myself were upset at being sent home on her date of admission and being told to come back 3 days later. It would have been helpful if we had been got in touch with previously and not had a wasted journey, plus all the emotional upset.' 'Her operation kept being cancelled. My husband is on contract work in Ireland. He paid £96 to come here, and then waited for 2 weeks here unpaid. He came again after her operation, £96 more.'

During admission

5.1 Information about ward routine

- | | |
|--|----|
| a) I knew what to expect before we came | 66 |
| b) I found out by asking the staff | 67 |
| c) the staff explained things to me before I needed to ask | 77 |
| d) I found out from other parents | 61 |
| e) no one gave me clear information
(251:27) | 22 |

One mother wrote, 'The nursing staff assume too much knowledge of the ward routine from the parents. They assume we know where the bathroom, toilets, playroom, kitchens are, without telling us. They assume we know when and where the children get fed, where to find a towel, a bed-pan, a gown. They assume we know that if medicine is left by the bed we are supposed to give it to the child; that if they say, "Yes, the child can have a drink", we are supposed to go and make it; that when the child wants to go to the loo and can't, we are supposed to get a pot, and save the contents for measuring and write up the results on a chart. They have forgotten that those things which are so commonplace to them are new for each patients' parents.

'When I have needed something for my child and there is no one in the room to ask, - a frequent occurrence - I have gone to find the nearest nurse. The answer I invariably got was, 'Go and ask (e.g.) Alison, she's looking after your room. I had to reply, 'Who is that?' At no time did any nurse announce that she was the one looking after us neither did any of them introduce themselves by name. There was also very little continuity of staff so that there were always lots of new faces around.

'The board with photographs and names of staff was an excellent idea, but it would have been more to the purpose if the photos had been those of the nurses and sisters we saw throughout the day. It would have been most useful to have displayed a timetable of the daily routine including mealtimes, doctors' rounds, medicine rounds, observation times, etc., so that we knew what to expect, and also so we could plan the children's nap times sensibly. (All my comment apply to the general ward. I cannot speak too highly of intensive care and all the staff there.)'

Parents also needed information about outside the ward. 'Money is such a problem, you need details about where banks and building societies are, grocers and newsagents. A map would be very helpful'.

5.2 Fitting into the ward

- | | |
|--|-----|
| a) we adapted quickly to the new way of life | 93 |
| b) it didn't take long to get used to routines | 134 |
| c) it took some time to settle in
(252:26) | 23 |

One mother whose child had stayed in hospital for a year said, 'We never settled in'.

Questions 6.1, 6.2, 6.3 and 7.1 could be analysed in much more detail. For this report, responses have been summarised into three broad categories.

6 Parents' satisfaction with facilities

Parents were asked to grade as 'good', 'fair', or 'poor' each of the following facilities:

6.1 Facilities for child patients - meals, snacks, beds, a safe place to keep their own things, toilets, bathroom, play areas, toys and activities, other (please describe).

77 parents thought the facilities were good to fair
131 parents marked an average of fair
17 parents thought the facilities for patients were fair to poor
(225:53)

There was most criticism of meals and snacks, 'disgusting' wrote some parents, mentioning the huge waste of uneaten food, unsuitable and unnutritious menus, lack of choice, especially for children from other cultures. 'He has to have the same meal every day.'

The arrangement in the second hospital of a good stock of food in the kitchen available for parents to make meals and snacks for their child was praised. 'Institutional cooking is rarely suitable for a child who is convalescing and has a poor appetite.' Mothers noted the extra feeding problems common with heart children, such as frequently a dislike of meat, and the need for more choice of menus and of tinned baby foods. With some children, discharge was delayed because they were not eating enough, however they hated the hospital food. 'The children are rushed through the meal, there is not enough table space and never enough chairs'. 'Snacks as far as I know are non-existent'. Another frequent complaint in one ward for the first part of the survey was about the domestics, 'they refused me access to the kitchen to get my child's food'. Later during the survey, a new sister managed to improve parents' access to the kitchen.

Another main concern was lack of anywhere safe to keep personal possessions. Lockers are not designed for children, who bring in more clothes and activities than adult patients. 'Need larger lockers and some hooks and a working radio.'

Parents were worried about noise for younger and post-operation children and for those who had had their pre-med. 'There seem to be no rules about 'lights-out' at bedtime, older children would still be playing and running in the corridors quite late' was a comment in the largest ward, with reverberating corridors and a playroom which is often closed.

Toilets and bathrooms in one hospital were described as dirty and cold. 'There is only one bath on the whole ward, only one tap head and the taps are wrongly labelled, the hot water comes out very slowly, there are no bath mats, there are not enough lights in the toilets and not enough are working.'

Some parents praised the play areas and toys, others criticised the provision for older children. In one ward, 'the playroom is closed so much for meals, or cleaning and in the evening and at weekends'. 'The floors are not clean enough for small children to play, they have to stay in their cots'.

6.2 Facilities for parents - meals, overnight accommodation, a safe place to keep personal belongings, toilets, bathroom, telephone, somewhere to relax, somewhere to have a cup of tea, a place to talk in private, somewhere to dry washing, car parking, other (please describe).

58 parents thought facilities were mainly good
151 parents thought they were fair
62 parents thought they were poor
(271:7)

Comments from both hospitals are given together because there are so many similarities.

Many parents wrote that being able to stay was the most important facility. 'It was all that mattered to me'. 'It is hard on men that they cannot stay.' 'More parent accommodation is vitally necessary.' 'There aren't enough beds for parents, especially for fathers who are not really considered involved or concerned.' Several parents asked me to convey their distress that the child's mother and father were often not able to stay together at times when they felt they most needed one another's company. Fathers complained of expensive and squalid bed-and-breakfast places.

Nursing mothers, particularly, felt hot and thirsty in intensive care units and longed to be able to get a cup of tea nearby. (This was introduced in one unit during the survey period.) In the other hospital, a father wrote, 'I've talked to other families and we all agree that a room should be set aside in the unit for us to make tea and coffee which we would provide. And we need toilets near here too, considering parents are sometimes sitting at their child's side all night.'

Parents found difficulties with domestic and canteen staff. 'The domestic staff is rude and utterly mannerless!' and some parents explained that they thought these difficulties made it harder for them to care well for their child. 'In times of stress, sharp words didn't

help much.' 'It is distressing enough to have a child in hospital, let alone the standards of hygiene, and cold and damp in the parents' quarters.' Parents were worried about fire risks in their rooms.

Apart from the emotional effects on parents of some hospital arrangements, some mothers were concerned about the physical strain. 'I am trying to breastfeed but I find walking from the parents' accommodation to the ward is too far, especially at 2am.' 'There are long queues for the bathroom. Toilets are only on the ground floor and fifth floor which is awkward. It would be very handy if parents could use the staff or patients' toilets.'

'You need a break sometimes, but this needs to be at times when you can leave your child easily. It is awful to have to go a long way to queue for the loo or for a drink when you have left your child screaming because you cannot wait any longer.' 'There are no comfortable chairs to sit on'. 'The one thing that would make life easier for a "mum" is a comfortable chair by the side of her child's bed, as we sometimes stay for hours by their side.'

There were problems for smokers and non-smokers in finding somewhere to relax. 'You need somewhere to relax near your child. Rest periods have to be short if you are off the ward.' In the first hospital a sitting room was open to parents, only for certain times during the day, and distant from the ward. 'There is nowhere to go in the hospital in the evening.' 'Everywhere seems to close down at weekends.' Other concerns were car-parking, telephones not working because not emptied often enough, thus adding to the strain of bad-news phone calls and of trying to keep the family in contact over long distances, nowhere to dry washing, to keep possessions safely, or to talk in private, especially when other family members were visiting.

6.3 Facilities for visiting children - meals, snacks, toilets, play and activities, somewhere to rest, other (please describe).

13 parents thought these were fairly good

83 parents thought they were only fair

75 parents thought they were poor

(181:97)

Officially, siblings are not allowed to eat in the ward or in the staff canteen. The out-patient canteen in the second hospital serves children's meals at certain times. The one in the first hospital serves only a very few snacks and parents were worried that there was nowhere for their other children to eat properly. 'So much of the patients' food is wasted. If only we could all sit down together for a meal as a family. I'm sure my sick child would eat better and we would gladly pay for this.'

'There is nowhere for siblings to see patients without disrupting the ward.' 'It is important for a child to have visitors but the number in the ward can become overwhelming. A lounge area is desperately needed. It is exhausting trying to control my other (handicapped) child in such a large ward so that she doesn't disturb others. A room with a door to contain her would make visits pleasant instead of a nightmare.'

6.4 Parents' preference for overnight accommodation

When/if I stay overnight I would prefer to stay:

a) somewhere near the hospital	31
b) in a parents' room in the hospital	146
c) in the ward where I could hear my child	59
d) in a put-up bed next to my child (269:9)	64

6 of the parents who ticked a) also ticked b) and 20 ticked both c) and d). Comments included, 'a) but if my child were younger or very sick I would want to be near him'. 'The staff chose not to call me at night which was against my wishes.' 'The change from intensive care to the ward is too great. If facilities were available it would be nice for a parent to stay with the child for the first night after intensive care. The care that my child has been given has been superb. What a pity that more money cannot be made available to make that care easier and more financially rewarding for the staff.' 'I want to stay because there are not enough nurses on at night in the ward.'

Two parents wrote that the second hospital's parents' house was beautiful, in contrast to the poor hospital accommodation, yet in common with many parents who gave low marks for facilities, they said they would prefer to stay in or near the ward overnight. 'The single thing that would have saved me most worry would have been to sleep by his bed at night.' 'A sick child would be more frightened and worried and need you to be with him.'

Parents' share in their child's care

7.1 Caring for the child

I am able to care for my child almost as I would do at home: at meal times, during bathing, first thing in the morning, at bed time, giving nursing care, giving medicine, controlling television, preparing for each new experience, calming my child's fears, comforting when my child is in pain, other (please describe).

[Parents were asked to grade each activity as 'most of the time', 'sometimes', 'hardly at all'. It was emphasised that these questions were not about the intensive care period, but about the pre-surgery and convalescent times in hospital.]

153 parents felt they could care for their child almost as they would do at home for most of the time,

95 could do so sometimes,

11 felt they could hardly care for their child at all.

(These 11 tended to be with children who had had little time outside intensive care.)

(259:19)

7.2 Parents' estimation of their involvement.

When sharing in the care of their child the parents:

- | | |
|------------------------------------|-----|
| a) are expected to do too much | 18 |
| b) can do as much as it suits them | 235 |
| c) could be allowed to do more | 16 |
- (269:9)

One mother wrote, 'I feel the staff rely too much on the parents' help. I wonder if he would have got all his meals if I had not been there to take him. I felt it was difficult for me to go out and snatch a quick meal because I thought he would not be safely supervised in my absence.'

7.3 Staff encouragement to parents to stay with the child

When my child has a medical test or procedure (apart from surgery or a catheter) usually:

- | | |
|--|-----|
| a) the staff ask me to stay with my child if I want to | 107 |
| b) I am allowed to stay if I want to | 139 |
| c) I am asked to leave | 20 |
- (266:12)

Parents criticised being asked to leave by physiotherapists in the first unit.

7.4 Staff interest in information from parents

If I explain what my child needs, on the whole the staff are:

a) pleased to be told	181
b) quite interested	70
c) not very interested (263:15)	11

7.5 Staff remembering parents' information

After I had told the staff about my child's needs:

a) they were usually careful to remember	138
b) sometimes they forgot	64
c) they hardly ever remembered them	9
or d) I did not ask the staff to remember any particular need (263:15)	51

Comments included, 'There was little continuity of staffing so whoever you told was never there when the need arose.' 'Personal requests were not passed on at shift changes.'

7.6 Parents' preference about leaving the child before surgery

Before the operation I would prefer to have stayed with my child until:

a) the pre-med was given	12
b) my child was taken out of the ward	94
c) after the journey to theatre	61
d) after the anaesthetic had been given (245:33)	78

Parents seemed to find this the most difficult question, and many wrote comments such as 'I was allowed to stay until he went out of the ward'. It was as if they felt that this was an area where they could not state a preference but ought to report what had happened. 'I stayed till she was taken out of the ward, no one minded.' 'He was taken away from us screaming.' Some gave an opinion such as 'The worst moment of all is when they go to theatre. It is not quite so bad if you're there until they are unconscious.'

8 Parents' concern about the risks of surgery

* When my child went to theatre I felt very concerned about:

a) the general risks of surgery	146
b) the special risks of heart surgery	225
c) the effects of the anaesthetic	129
d) how my child felt when going to theatre	94
e) how my child would feel afterwards	156
f) how much my child would benefit from the operation	137
g) not one thing in particular	18
h) other (please describe)	20

Some parents added euphemisms about fatal surgery, 'worried that he would not come back again'. A few did not identify particular concerns but said 'I felt hundreds of worries,' or, 'I felt helpless because I was ignorant about so many things of his heart condition and future.' Some were very specific, 'The pre-med hadn't worked. I felt very upset at the thought of him entering theatre awake and alone.' A Nigerian father worried that there might be a power-cut.

9 Help from other parents

Some of the other parents in the ward:

- a) helped to explain the ward set-up to me;
- b) helped me to understand more about my child's condition
- c) helped me to know more about my child's treatment;
- d) gave me other useful information (please describe)
- e) I did not get any useful information from other parents in the ward

- 63 parents said they had no help from other parents.
 - 101 parents ticked one aspect of help
 - 45 parents received 2 kinds of help
 - 30 received 3 kinds of help
 - 17 received 4 kinds
 - 6 parents added a fifth form of help in their comments.
- (262:16)

The purpose of this question was to see the amount of help parents felt they received, rather than the types. Some parents who said they had no information added that they gave it to others.

Useful information was often received only informally through other parents, such as 'police parking permits, very important', and a reduced fares scheme at the second hospital, and details of many hospital services.

Many comments stressed that the vital help from other parents was not information but moral support. 'To know I was not alone in the way I felt about my son's condition'. 'Give me more strength on day of surgery and afterwards', 'a great comfort', 'a general shoulder to lean on', 'helped by understanding my feelings'. 'The sympathetic shared experience of depression helps relieve anxiety and frustration.' 'Talking with other parents helped to put our problems into perspective.'

10 Parents' views of the nurses

10.1 Nurses' readiness to talk with parents

a) the nurses chat with us several times a day	122
b) the nurses find time to chat with us sometime during the day	109
c) the nurses seem too busy to talk unless they are doing something for our child	38
d) the nurses have little time for talking to us (275:3)	6

10.2 Nurses' understanding of children's feelings

a) all the nurses show understanding of the children's feelings	138
b) most of the nurses seem to have some idea of how the children feel	126
c) too few nurses seem to realise how the children feel (274:4)	10

10.3 Nurses' sympathy for parents

a) all the nurses seem to sympathise with the parents	117
b) most of the nurses have some idea of how the parents feel	135
c) too few nurses seem to understand what it is like for parents in the ward (276:2)	24

Many comments of praise and gratitude were added. 'The nurses were excellent in every way, very loving people, they don't get paid enough.' 'Nursing staff excellent, very informative, very polite. I was very pleased and impressed with all the nurses.' 'The nursing staff is very wonderful and helpful at all times. Everyone I met was great. All I have heard about this hospital before arriving was true. You are all great, many thanks all.' 'The nurses can only be described as wonderful. They are so busy but they help as much as they can.'

A few parents thought some of the nurses seemed rather casual or unfeeling. Some thought that some nurses would improve with experience, or if they had children of their own. 'I'm sure the most important thing for parents is not the facilities for parents, (other than the ability to be near one's child) but the friendliness, helpfulness, etc., of the staff on the wards. It only takes one uncommunicative nurse to leave one depressed and tearful for no good reason. This does, however, occur only occasionally.'

10.4 Nurses' skills

Parents were asked to grade the following five questions under the headings 'almost all nurses', 'many nurses', 'few nurses':

The nurses:

- a) are always kind and gentle
- b) are very skilled
- c) are ready to show parents how to give nursing care
- d) are ready to explain things which parents should be careful not to do
- e) encourage parents to do as much as possible for their child

116 parents thought very highly of the nurses
110 parents had some reservations
35 parents were fairly critical
13 parents thought that few nurses showed these qualities.
(274:4)

10.5 Detail of nurses' information

Overall, when I am given information by the nurses:

- a) they always seem to give me the details 132
 - b) they seem to tell me enough 107
 - c) they leave lots of gaps 34
- (273:5)

10.6 Nurses' workload

On the whole I think the amount of work for nurses is:

- a) too much 89
 - b) as much as they can cope with 172
 - c) hardly enough to keep them busy 8
- (269:9)

Comments included, 'depends on the nurse'. 'I thought they were short-staffed and the nurses and doctors coped beautifully with much patience.' 'I don't like the idea of leaving a nursery nurse in charge of babies with heart problems, and only one nurse to look after 4 to 6 babies at a time.'

Several parents were worried at the sudden change from intensive care nursing to the short staffed ward. They felt the children would prefer to stay in a quiet, high-dependency area for a day or two in between.

11 Parents' views of the doctors

11.1 Doctors' work load

On the whole I think the amount of work for doctors is:

a) too much	105
b) as much as they can cope with	143
c) hardly enough to keep them busy (254:24)	6

Comments included, 'Not on the ward often enough for us to know', and 'depends on the doctor'.

11.2 Doctors' time for talking with parents

When I want to talk to the doctors, often:

a) they seem far too rushed	54
b) they hardly allow me enough time	33
c) they give me just as much as I need	160
d) they seem to have plenty of time to talk (275:3)	28

One parent added to d) 'even though they haven't really', and as with all the questions about the qualities of the hospital staff, many people found it hard to generalise.

11.3 Access to doctors

The easiest time for talking to a doctor is:

a) during a ward round	146
b) when I have asked a doctor to arrange a time to talk to me	44
c) if I can find a doctor who doesn't look too busy	52
d) other time (please describe)	14

19 more parents ticked a mixture of answers, several said 'any time', some changed b) to 'when I ask the sister to arrange a time', one said, 'It's never easy.' 'Although the easiest is a) it is always difficult because they

have so many doctors with them.' Parents mentioned just before or after the operation as particularly important times, and thanked surgeons for coming to talk to them.
(275:3)

11.4 Grades of doctor

On the whole the most helpful medical information was given to me by:

- | | |
|--|----|
| a) a junior doctor | 16 |
| b) a registrar | 48 |
| c) a consultant | 98 |
| d) a doctor whose grade I do not know | 54 |
| or e) none of the medical information was very helpful | 3 |

52 more parents ticked more than one answer.
(271:7)

Many parents seemed confused about doctors' names and status, for example, during discussion they often described registrars as consultants, SHOs as registrars or as medical students, and many did not know who their child's consultant was because, in one unit, children tended to be admitted under the name of one consultant, but seen during the week by another. There was also uncertainty about the relationship between physicians and surgeons. The 'doctors' were seen as the surgeons' assistants. 'Mr -- (surgeon) sends his team out to clinics, but he stays here at the base.' 'There are so many doctors appearing at different times. It would be helpful if they wore badges with their name and status.'

11.5 Doctors' manner

The way the doctors talk to me is usually:

- | | |
|-----------------------------|-----|
| a) very pleasant | 163 |
| b) fairly pleasant | 103 |
| c) rather rushed and abrupt | 10 |

(276:3)

Comments included, 'To my mind, after 7 visits, the main aggro is lack of time by doctors to talk.' 'There is no continuity of ward rounds.' 'Doctors and nurses generally resent too many questions.'

11.6 Doctors' volunteering information

When I need information about my child's treatment:

- | | |
|--|-----|
| a) they usually seem ready to tell me
all I know before I ask | 122 |
| b) I hardly ever need to ask for it | 70 |
| c) I often need to ask for it | 74 |
| d) I always have to beg for information
(274:4) | 8 |

11.7 Detail of doctors' information

Overall when I am given information by the doctors:

- | | |
|---|-----|
| a) they always give me the details | 142 |
| b) they seem to tell me enough | 95 |
| c) they leave a lot of gaps
(266:12) | 29 |

11.8 Nature of medical information during admission
[as opposed to information before admission]

* During our stay in the ward I would have liked more information about:

- | | |
|---|-----|
| a) my child's heart condition | 70 |
| b) what the tests would involve | 42 |
| c) why the tests would be given | 35 |
| d) how the treatment would be given | 40 |
| e) why the treatment was given
(such as medicine or the operation) | 45 |
| f) the risks of the treatment | 74 |
| g) the effects on my child | 79 |
| h) the future outcome for my child | 106 |
| or i) I have had enough medical information | 115 |

11.9 Difficulties with medical information

* When the doctors explain about my child's condition or treatment:

a) they go out of their way to make sure that I understand	154
or it is sometimes difficult because:	
b) they use too many technical words	49
c) they use easy words but only give a bare outline	41
d) one doctor will give a very different picture from another	43
e) English is not my first language	18
f) English is not the doctors' first language	29
g) my child's condition is very complicated	27
h) I feel uneasy that other people are listening and there is not enough privacy	37
i) it is not easy to know what kind of questions to ask	80
j) my child is listening or interrupting	21
k) other difficulty (please describe)	10

Parents added comments about combinations of difficulties such as trying to follow a soft, foreign accent in a noisy ward. Some tried to show an order of priority, stressing the importance to them of a particular problem. Lack of privacy to talk was a serious concern to parents and seemed to be held to be the most avoidable problem. Some aspects were seen as largely unavoidable, or at least not within doctors' power to resolve; many parents ticked a) but went on to tick other answers.

With i) parents seemed to feel that they shared responsibility with the doctors, commenting on the catch 22: it is difficult to know what to ask until you have some knowledge, but doctors tend to give information in the form of answers to questions. 'It's not easy to know what questions to ask until the doctor has gone when I think of plenty.' 'Doctors and nurses only tell the whole story if parents ask them.' 'Difficult to know how much time you have to discuss things. Also, doctors give the impression that they do not expect parents to understand much of what's going on. I think they should try to find out what parents already know and try to correct misconceptions or fill in information where parents would need more.' 'I think they only tell you what you need to know at that time rather than tell you things you are not going to remember or understand.' 'Doctors haven't tried to explain. We are impressed with very helpful nurses and playworker. Doctors seemed to ignore us and just did things to our child without saying a word.'

11.10 Communication between parents and doctors

When the doctors need to tell me something about my child:

- | | |
|---|-----|
| a) they ask me for my view as well | 105 |
| b) they only tell me what they think | 139 |
| c) they often leave it to someone else to tell me
(257:21) | 13 |

Comments included, 'they are prepared to listen to me'.

11.11 Parents' confidence in doctors

- | | |
|---|-----|
| a) I have complete confidence in everything the doctors do | 140 |
| b) overall my confidence in the doctors is quite high | 117 |
| c) my confidence in the doctors is
not as high as I would like | 12 |
| d) I have very little confidence in the doctors
(269:9) | 0 |

One parent wrote, 'Nurses and doctors do a splendid job in what seem at times difficult situations. My child has had constant care and love and I have every faith in what they did. My son owes his life to these people and I think they should be rewarded and recognised for what they do. I found them helpful and informative. I shall be eternally grateful to every one of them.'

12.1 Completeness of information from doctors and nurses

The doctors and nurses:

- | | |
|---|-----|
| a) always seem ready to tell me the whole truth | 189 |
| b) sometimes seem to keep things back
to avoid worrying me | 57 |
| c) often want to tell me as little as possible
(264:14) | 18 |

12.2 Certainty of information from doctors and nurses

I feel that most of the staff are:

- | | |
|--|-----|
| a) sure about the information they give me | 196 |
| b) not always sure about the information they give me | 61 |
| c) rather vague and uncertain in what they tell me
(267:11) | 9 |

13 Information from other hospital staff

I was pleased to have extra information from:

- | | |
|---|-----|
| a) the playworker | 49 |
| b) the hospital teacher | 5 |
| c) the radiographer | 14 |
| d) the physiotherapist | 129 |
| e) other (please describe) | 4 |
| f) I have not had any extra information | 98 |

'Other' was named as the accommodation officer. One hospital has no teacher, in the other, parents added notes thanking the ILEA staff. Parents used this question to comment on other staff and some criticised domestic staff. 'A difficult ward orderly can cause distress to children and parents. One there at present is totally unsuitable for the ward.'

14 Help from the social worker

The social worker helped us:

- | | |
|--|-----|
| a) with getting fares help, or benefits, or parents' accommodation
(Many parents who ticked this were referring to the accommodation officer, not the social worker.) | 71 |
| b) by helping other staff to understand our views
or by just being someone to talk to | 45 |
| or c) we did not have any help from the social worker
(259:19) | 159 |

Many parents wrote that they did not need or want help from the social worker, or that the help they had received had been during a previous admission. Many others added that they greatly needed help which was not offered. 'We have never seen a social worker although we have travelled more than 200 miles and our baby has spent all his five months in three hospitals.' 'Most children here are facing very serious operations. It is a worrying time for parents but no form of counselling or advice was available to my wife and myself either socially or psychologically. As in every hospital we have visited with our child, parents are treated as a necessary but unwanted intrusion.'

During most of the survey period, the cardiac children's social worker post in one hospital was frozen by the local authority which considered it could not meet the needs of local people and that social services for a national referral centre should be funded nationally, not locally. The social worker in the other unit did not have time to arrange financial or counselling help for all the families in need of support.

15 General comments

Some parents commented on health service economics, for example: 'The limited space and resources are distressing for children. The government should get its priorities straight, to switch the billions of pounds from nuclear warfare and concentrate on saving lives, especially of the children. The staff do wonders on such limited facilities.'

Discussion

The purpose of this paper is to report the results of the survey to the hospital staff caring for children in the two paediatric cardiac units. Although the parents' replies raise many questions for discussion, in order to keep down the number of pages, I will deal with only a few of the main questions here.

Bias

Bias is a consideration in the survey subject matter and in the survey method. The subject matter here is not objective facts, but subjective preceptions. Each stage during a child's admission for surgery may be regarded as an emotional time, likely to alter parents' opinions of hospital care, and therefore to 'distort' the results of a survey. However, the notion of distortion assumes that there is a definite parental opinion, such as one which parents hold to calmly and rationally after the crisis of the child's admission. It may be more helpful to see parents' opinions along a spectrum from satisfaction to criticism, changing at times although possibly holding fairly constant, and this survey is an attempt to capture general perceptions at a certain stage, a few days after surgery.

Another notion, implicit in the concept of distortion, is the idea that a general satisfaction level can be measured, and that 1,000 parents, chosen more carefully to be representative, would show a higher or lower level of satisfaction than the views of parents reported here. Although general levels are important, I hope that this survey illustrates the wide range of parents' views, and the need sensitively to be aware of and to provide for a variety of needs, rather than to take notice only of the average or the majority.

I have tried to avoid bias in the survey method by the many interviews and the pilot before deciding the final questions. Also, by using open questions and asking for comments so that parents were not confined to answering only pre-set questions which might ignore crucial issues or over-emphasise minor ones. Thirdly, by coding and presenting most replies exactly as the parents answered them.

The greatest problem is how to convey the feelings of the parents, as some of them asked me to do. Many felt extreme gratitude and admiration for the staff. Some parents seemed determined to remain cheerful and appreciative as a method of getting through a difficult time. There were parents who ticked 'good' for facilities, and yet in one case a mother and grandmother were filling in a questionnaire, after a night of sleepless anxiety, sitting on the playroom floor because there were not enough chairs. In another instance, a mother, whose daughter died after spending almost her entire two years in hospital and usually on oxygen, had a baby ten months younger. There were only hard upright chairs near the bed, no

sofa or easy chairs, so that this mother could never sit down with both children together, her time always had to be divided between the two.

With a third group of parents, I gained the impression of serious unhappiness, anxiety and loneliness which it is impossible to describe. A few questionnaires show a series of ticks denoting dissatisfaction and isolation, parents in need of help but who seldom talk to nurses, doctors, other parents or a social worker.

When there are too few resources, the staff try to respond to requests for help, but they have little time to search for those who need help or to go around offering it. Unfortunately, some of the parents in greatest need of help are least able to ask for it. It is likely that the most satisfied parents are confident and have the social skills to establish good relationships with the staff and other parents, to ask for help when they need it and this reinforces their confidence and satisfaction. However, some parents who have difficulty with relationships in the hospital can fall into a downward spiral of problems.

It can be argued that these specialist units are intended to treat children's hearts and not parents' feelings. Yet there are two ways in which children's medical care and parents' mental states are related, and these are two reasons for my attempt to convey something of the parents' subjective 'biased' responses.

The first is the practical issue. Parents who feel good are likely to give effective help to their child, to the staff and other parents, whereas unhappy parents potentially are less able to share the burden of care with others and they may increase it. Since some unhappiness and anxiety is inevitable, it is even more important that unnecessary difficulties are reduced or prevented.

Second is the issue of confidence. In a witty article about being a patient, a doctor described an 'infinitely depressing ward' with dreadful bed, baths and food. 'An ignorant layman might well have been forgiven for wondering if the professional standards were commensurate.' (British Medical Journal p1458, 31.5.86) Parents have no means of judging medical and surgical skill. They can only hope that doctors share their understanding of their child's best interests, and base their hope on the care they can see being offered. If hospital services appear to be indifferent or even hostile to the welfare of the family, then it is possible that parents may wonder if the professional standards are commensurate, that there may be indifferent or hostile aspects of medical and surgical care. This would set up very serious, even if unconscious or irrational doubts, which would increase the strain on parents and would not help the children.

Parents were approached a few days after surgery as a stage when they were most likely to have time and attention to spare for completing a lengthy questionnaire. Here are some reasons why the results might be expected to be biased towards satisfaction rather than criticism.

1. Parents' relief and gratitude for their child's successful treatment.
2. Reluctance to criticise non-medical and therefore comparatively minor concerns, when highly satisfied with major issues of skilled medical and nursing care, which were outside the range of this survey.
3. Reluctance to criticise while the child was still under hospital care, (parents were expected to be too busy after discharge to post back the

questionnaire) and when total anonymity was precluded by the personal details recorded.

4. Exclusion of groups likely to be experiencing the most difficulties - parents of emergency cases, of neonates, non-English speaking parents, those who were unable to be with their child in hospital or whose child was failing to recover, or who showed more than usual distress. Parents who could cope with this survey were more likely to be coping well with the hospital experience.
5. Parents' anxiety that feeling ill-informed or uninvolved or critical is somehow due to their own ignorance, negligence or ingratitude; they may wish to record more satisfaction than they feel.

Possible reasons that the results may be expected to be biased towards criticism:

1. Parents are likely to be exhausted, still anxious and less than normally able to tolerate difficulties.
2. Problems which can seem less serious later may seem overwhelming at the time.
3. Anxiety and dissatisfaction about esoteric medical matters which parents cannot clearly identify may be displaced on to simpler matters.
4. Parents may have unrealistic expectations about the quality of information and facilities.

Optimal standards

This last point, raises the question: what are realistic or optimal standards of information and facilities, given the wide range of opinions held by parents and professionals and the limited resources, space and time available in hospitals? Theories underlying the practice of involving parents in their child's hospital care may be summarised as:

1. Parents can contribute positively towards the physical and emotional care of their child in hospital.
2. Their absence can cause distress for the child.
- 3 Children often need parents to act as interpreters, explaining their needs to the staff and explaining experiences and staff requests to the child.
4. Parents' own anxiety and distress can adversely affect the child's physical and/or mental welfare.
5. Appropriate preparation and information can aid post-operative recovery and young children often need information to be put into familiar terms by their parents before they can absorb it.

Hospital staff vary in how much they agree with these theories, how much importance they attach to them, and how much practical support they give towards implementing them.

On the other hand, most parents consider at least some of these points to be crucial in their child's welfare and that, by implication, minimally adequate standards of information and facilities will be those which allay unnecessary unease in the family, and which encourage rather than deter parents in caring for their children.

Parents have continual, direct experience of how hospital practices encourage or deter them in caring for their child. This survey was not undertaken as a kind of WHICH? report for consumer parents, but to examine

how children's physical and mental welfare can be affected through the family's experience.

Hospital policy

There is a tendency to use hospital resources for patients and for staff, leaving patients' relatives to fit in afterwards. One mother explained the difficulty.

'When I trained as a nurse 11 years ago, the nurses did everything for the children. But now I am here as a mother, there are far fewer nurses, and I find the mothers are expected to do almost everything. I think this is right, but we cannot care for the children properly if we are not shown where things are kept, or not allowed into the kitchen, or to stay with them at night.'

Both hospitals in this survey are unusual in being post-graduate teaching hospitals, with exceptionally serious cases and pressure on resources. Unlike most teaching and district hospitals with their district health authorities, community health councils and joint planning groups, these two hospitals have no formal lay representatives in touch with patients on their planning or management committees. As a result, while there are strong advocates on these hospitals' committees for children's medical and nursing interests, there is not such effective advocacy for their psycho-social interests. One example is that in the second unit, a third consultant surgeon has been appointed, but there has been no accompanying increase in the already seriously overstretched non-medical services for patients and families.

When decisions are made about children's non-medical care, it is likely that services will be provided which hospital authorities consider are best for the hospital or best for the patients, but these services may be quite different from what children need or what parents consider to be in the child's best interests. Children, parents, social workers and junior nurses in close touch with the children may hold different values and ordering of priorities from those of senior doctors, nurses and administrators. However, hospital committees considering services for families tend to be dominated by, or even solely composed of, the latter group.

Recommendations

Rather than review the practical, and often inexpensive, suggestions made by parents through this report, I will only add that if services are to match more closely the needs of families, as expressed by parents:

some method will need to be found of obtaining regular and representative reports from children and parents, social workers and junior nurses about families' psycho-social needs;

the reports would be considered by the hospital authorities together with advocates of children's non-medical interests. They would also decide on the values and order of priorities on which decisions about the medical and non-medical care for children are based;

senior nurses, administrators and social workers would be given the time and resources necessary to put the decisions into practice.

I thank the parents and children who took part in the survey, the staff in the two hospitals who advised on the survey and enabled it to be carried out, especially Dr Shinebourne and Dr Rees, the ward clerks who received the replies, Andy Thompson who helped with design of the questionnaires, and Paul Highton who spent weeks teaching me how to use the Brompton Hospital computer. The survey was sponsored by the Economic and Social Research Council.

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NURSING SATISFACTION STUDY

ROSE GALLERY AND P.I.C.U.

BROMPTON HOSPITAL

The purpose of this study is to record the views of the paediatric nursing team about their work and conditions in the hospital. Particular attention is paid to nurses' satisfaction and difficulties in their work. The study is also concerned with factors which attract nurses to come to work at the Brompton Hospital and to stay here.

What do nurses consider to be the most important aspects of nursing and of patient care? How much do nurses feel able to attend to their priorities and how much does hospital policy and practice support nurses' order of priorities?

The main findings of this survey are that nurses would prefer to concentrate more on caring for people; they value personal, individual care for both patients and staff but they feel that hospital practices attend to different priorities. Nurses consider that their learning and inservice training is grossly neglected. The nurses see the Brompton Hospital as mainly concerned with adult patients, to the detriment of paediatric patients and staff.

The study findings are reported in sections which reflect the main concerns of the nurses.

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Some nurses were anxious to stress that they hoped their answers to the questionnaire would not be taken as criticisms, but as constructive attempts 'to help to improve the standard of care and staff relationships.' We share this concern.

We would like to thank all those who enabled this study to be carried out, especially the nurses who completed the questionnaires, and Mr Tom Kerane, Mrs Sue Rees and Dr Elliot Shinebourne.

Bridget Comer and Priscilla Alderson

October 1986

Survey method

After a pilot trial, questionnaires were given to 74 nurses during August and September 1986. The results were analysed on the hospital computer minitab system.

58 completed questionnaires were returned, a return rate of 79%. The questionnaires were anonymous. For information about the nurses who took part in the study see appendix, table 1. The data could be analysed in much more detail than is reported here.

Personal care

Nurses value personal care and concern for individuals highly, both for patients and staff.

Care for patients and families The nurses would prefer to spend more time on talking with parents, talking and playing with children, discussing and planning work with other nurses, and teaching new nurses in contrast with impersonal activities.(Table 3)

Most nurses thought that ward routines should be centred around the patient's day, rather than around nursing or medical routines, (table 2) and they stressed the importance of this in their comments. 'Less feasible on PICU but certainly essential on Rose'.

They were concerned about neglecting patients. 'I was so busy preparing the bed and trying to find the equipment, I felt I was rushing everywhere and doing everything except looking after my patient.' In table 8, most nurses thought that the pace of work was often too rushed. 'Sometimes it is impossible to pace the work to suit the children's needs, such as the babies' feedtimes.'

Patients' and parents' distress The nurses acknowledge that personal feelings play a significant part in their work. Many feel upset about patients' distress. (Table 27) 'I have become used to it, but obviously seeing a child upset on a ventilator or having suction is upsetting for me.' 'You still get upset sometimes when you have time to think about it.' 'One gets used to cardiac arrests, but it is still upsetting if they carry on working on a child when there is not much hope, as the result can be a brain damaged (or dead) child on a ventilator for weeks and very distressed parents.'

The problems which caused most concern were not actual medical procedures but children seeming in pain, 'frustrated in that I'm unable to use adequate analgesia', and problems which created uncertainty, such as, children going for very high risk surgery and cancelled surgery. Frequently it is the nurses who have to tell parents when surgery is cancelled; they have to explain or excuse a system over which they have no control and they have to cope with the main burden of the families' distressed reaction.

Very few nurses thought that 'firmness with parents' was necessary (table 10c), 'except on the very, very rarest of occasions'. Yet nurses have to work with 'aggressive and difficult parents' (table 20) 'although it is their way of coping', one nurse added.

Information Nurses were critical about the amount of medical information given to parents. (tables 13, 20) 'Parents need to be assertive to get time from staff to explain everything clearly. Many people feel unable to do this, as if they must be grateful etc. and only receive attention if situation is CRITICAL.' 'Doctors do not volunteer information generally, parents get it if they ask enough questions.' 'Long term patients are sometimes neglected, difficult to get surgeons to explain the operation.' 'Too little consultant contact with very sick child and long term child.' 'As a sister I feel I give far more medical information to parents than doctors do.' 'Nurses sometimes have to sort out misinterpretation of what doctors have said.' 'Parents often need clarification and repetition.' 'They are not told in a manner they can easily understand.' 'Parents think the ward round is an important time for getting information, but in PICU they are often ignored if allowed to stay, or asked to go, so find it difficult to ask doctors themselves.'

Ward rounds Many nurses saw ward rounds as an opportunity to draw attention to personal aspects of patient care. They wanted 'to be given the opportunity to be more involved', 'to be asked my opinion,' 'to speak about the patient you know well and care for', 'to bring up specific points', 'to convey parents' feelings which they can often express to me, as the nurse looking after their child, but they are unable to discuss on a large intimidating ward round.' 'To put over to the medical team nursing views and parents' and children's feelings and worries.'

In order to achieve these aims, nurses needed 'to be recognised as an important part of the team.' But 'unfortunately rounds are aimed at medical staff only! With no regard for nurse's time or her carrying out her duties.' 'Rounds are not made to be welcome to anyone bar the round themselves, nurses generally are ignored or pushed aside and not spoken to.'

Besides feeling that they ought to contribute more to ward rounds, nurses also felt that they should gain more from them of benefit to patients. 'Rounds are frustrating, especially when you have a sick child and nothing constructive is said or done.' 'In Rose the nurse looking after an area never gets feedback about the round from the person in charge who nearly always does the rounds.'

'I feel that children can find the ward round very frightening, so although I feel that nurses could learn much more, I also tend to think that the round should be over as quickly as possible.' 'I think children see them as scary and awfully long, maybe discussions could be kept until in the office.' (Tables 11, 12a + b.)

Staff shortages There were many comments about the difficulties and stress caused by staff shortages and what this meant to patients. (For nursing cover see table 5). 'There are not enough trained nurses to cope with the paediatric intensive care workload.' 'To leave one nurse in Rose (nursery nurse on occasion) looking after 6 babies could be dangerous.'

'The most worrying problem is the amount of emotional blackmail used recently to admit sick patients when there are no nurses to cope, to the point of danger to patients. The already resident patients become more ill. The nurse may feel very guilty of not observing the child adequately.' 'We need to say NO to surgeons when you have no nurses, equipment, space, to do an extra case!'

Care of the dying child and the family Many nurses feel very sad and some have a great sense of failure about the care they try to provide for dying children and their parents. (Tables 16-19) Some nurses often think and worry about these families when away from work. (Table 22). 'It's very difficult to switch off some days.' 'It's very hard not to think about work when off-duty if it has been extra busy or there has been a lot of deaths.'

Nurses wrote many comments about the extra difficulties in caring for these patients, the problems in trying to respond with sensitivity and tact to a wide range of reactions from the families, and the need for counselling and teaching to help nurses to provide better care and to cope with their own distress. 'I am personally very frightened of dying and find it hard to "cope" with the older dying child because of my fears. I know how to help but I do have the sense of guilt and failure because of my fears.' 'It might help if we all had some help in caring for dying patients and bereaved parents, the skills are not just learnt by experience, I believe.' Most of the nurses' answers about the care of dying children will be given in a separate report which is being prepared and will also include the views of bereaved parents.

Concern for nurses

As well as worry about patients, nurses had strong feelings about the quality of their work and their relations with other nurses. 'As a course member I worry about lack of knowledge, being unable to cope, I'm cross with myself for not knowing.' 'Often I leave work burdened by problems, but very aware that I'm entirely isolated if the only sister on duty.' 'I worry if I know a nurse is unhappy, try and think of ways I can help. Worry whether I am doing enough, "pulling my weight", and that when I'm run down I can't continue to work on PICU.' 'One effect of their worry is that a high proportion of nurses want to take sick leave because of pressure of work, (Table 24a) but feel unable to do so (Table 24b) partly because this would increase pressure on other nurses.'

The unit nursing team Of all the hospital staff, nurses work in the most close and intimate contact with patients. Questionnaire answers suggest a feeling among nurses that because their work makes such heavy demands on their personal and emotional resources, they depend greatly on help and support from colleagues and friends. Nurses need personal support to enable them to provide high standards of personal care for patients. If they have a sense of well-being it is easier to care well for patients; if nurses feel unhappy it is harder for them to give patients the best care and it is harder for them to resist depression about the patients' distress.

Most nurses expect to receive sympathy and help from other nurses if they have a personal problem which affects their work. (Tables 21a & b) Only two nurses said they thought that personal problems should not affect their work. One nurse said, 'unfortunatley what you expect and what you get are not related.' High scores for table 21 may express what nurses hope for, rather than what they receive.

Expectations varied, depending on nurses' personality and experience. 'From personal experience, people are always willing to listen and to help if able.' 'I would expect help, but in this hospital no doubt you would end up with criticism from everyone - basically because the attitude here is "don't care".' 'More often than not, if you are unhappy about a babe, you are told it is nothing, you are causing too much of a fuss.' Some nurses were

much affected by whoever they were working with and worried when off duty about who would be on their next shift.

Some found the nurse support group very helpful (table 21) others did not. This suggests that a variety of kinds of support for nurses is needed. 'I feel support should be there at all times from the senior surgeon and nurse, not just discussed at a meeting.' Nurse support meetings can serve two important purposes. Firstly they can treat distress by helping nurses to feel less isolated, anxious, and inadequate in their work. Secondly, they can help to prevent avoidable distress by evaluating hospital systems and advocating improvements. Some nurses were worried that meetings served only the first purpose and 'turned into negative moaning sessions.'

Friendly working relations were seen as directly affecting the quality of patient care. 'The friendliness of the girls always tells me I am not alone, they are always willing to explain something you are unsure of.' 'The most help is from bedside discussions with members of the medical and nursing team.' Senior nurses worried about having so many learners and nurses without full training in the team, and experienced nurses found that they carried an extra heavy workload, which was seldom acknowledged. Willingness to teach and to ask for help was very important for the patients' safety. Most nurses thought the wards were usually pleasant places to work in, (Table 7) and for many, good relations within a highly committed team were among the most satisfactory aspects of their work.

The nurse within the hospital Nurses need well organised support from hospital staff and systems to help them to work as effectively as possible, to lessen, not increase, avoidable problems and strain in caring for sick children. On the whole, do the nurses experience support or lack of support in the hospital?

Nurses' views about medical staff and ward rounds (tables 2, 11, 12a, 12b) have been mentioned, as have nurses' views of medical information giving. (Tables 13, 14, 15 and 20) Tables 23 and 28 show that nurses on the whole are satisfied about relations with non-nursing hospital staff. Some said that they found xray staff sometimes unhelpful. Shortage of equipment and problems such as ventilators breaking down unexpectedly put much extra strain on nurses, extra work and extra worry.

Concern for the individual (Table 6b) There was criticism of nursing management for apparent indifference to nurses. 'Nobody seems to care whether you stay or leave.' 'There is nothing to encourage you to stay.' 'I look after myself as best I can but there is a great lack of support from others to me,' 'the lack of emotional support and praise.' 'Lack of trust and insisting in treating nurses as though they are new, although some of the nurses have been working here for 3 years or more.' 'No one seems to notice or care if you feel too unwell to work. Generally I find you are very much on your own. You get a lot of help and support from nurses on your level, but virtually none from the higher hierarchy.' You need 'the ability to do the job without knowing how well/badly you are coping in the eyes of your superiors'. 'You never get any thanks from the nursing office.' 'Nurses views and new ideas are ignored.'

Many nurses thought that there was urgent need for a 'dynamic' full time paediatric nursing officer; someone who could represent the separate interests of paediatrics without also having to represent other, competing departments. Also, someone with time 'to talk and take an interest in each

nurse', to get to know the nurses, 'to take an active share in the care of patients', and 'to give more help and support and appreciation.'

Nurses did not expect much help and support from nurse administrators. (Tables 21a and b.) Nurse managers are supposed to provide support and counselling, but nurses are reluctant to discuss personal difficulties with those responsible for assessment, discipline and job references.

Working conditions (Table 6) The comments were mainly about working conditions which caused unnecessary inconvenience and discomfort, leading nurses to feel undervalued. On uniform: 'Especially in summer, what other profession would choose to wear high collar dresses, tight aprons and closed-in shoes!' 'Unfair annual leave system, some have one month, others have one week in summer.' 'I saved for years to go home to Asia but I was not allowed to accumulate annual leave and go for more than four weeks without resigning from the hospital.' 'I work too many nights together but no one in authority takes note. Working ten long days then two off with no regard to the nurse.'

PICU is very pleasant, 'spacious and airy with a marvellous view', but the changing room is 'boiling in summer, freezing in winter.' 'Filthy toilet with no window!' 'Shower does not work.' 'We need a non-smoking place to relax and more comfortable chairs.' 'There is nowhere to relax for staff or parents.' 'Accommodation in the nurses' home is dreadful and often depressing,' 'not enough showers.' 'When parents stay in the nurses' home you feel you can never get away from work and speak freely.'

Many nurses said they never went to the canteen. 'Service is slow, n.b. we only get half an hour break, there isn't time to change, wait for the lift, queue for food, get back and change. The canteen staff are often rude and unhelpful.' 'We should have meals or sandwiches brought up to the unit as we don't have enough time to go to the canteen. Theatre do, so why can't we?' 'We need food at night but there is nothing.'

'I feel I am just a work machine.' Tables 10a, b and c show that nurses accord highest value to qualities concerned with caring for people, rather than to technical and organising skills, while acknowledging that these are also important. One sister added 'approachability' as a very important quality, and another added 'resources and ability to support everyone in every conceivable situation.'

The tables also show that nurses do not feel expected to use their caring qualities as much as they would like to use them. Tables 29a and b suggest a difference between nurses' priorities of personal care and what they perceive as the hospital authorities' priorities of technical efficiency. There is a general feeling that 'nurses and patients are just numbers to senior staff, who don't look at quality and experience of staff or at the needs of patients.' 'I feel I am just a work machine.' It is difficult for nurses to want to feel part of a hospital system which they consider does not treat individuals - patients and nurses - with care and respect.

One response to this report could be to criticise nurses for being too passive. If they are unhappy why are they leaving the hospital instead of working for improvements? Nurses' ideas and efforts to improve hospital care are described in other sections. The crucial question here is how much will nurses have to work with difficulty to obtain better nursing practices and working conditions, and how much will changes be made in

management attitudes and arrangements to help nurses to work more effectively?

Although nurses, for example, want to speak more during ward rounds, (Table 11) they marked 'confidence in talking to groups of people' as not very important. (Table 10c) While it could be argued that nurses ought to be more assertive, it seems that nursing attracts people concerned with gentle and sensitive caring. If they became more assertive (which might entail losing certain sensitivity) they would perhaps leave nursing to find work which allowed them more autonomy. Instead, nurses feel that they are expected to spend much of their time in obedience to routine. 'Imagination is very important, I don't get much opportunity to use it however.' 'Once the tasks are learned there is no new challenge.' 'I am expected to do things without being given a good reason, I'm not able to master the situation.' Sisters wrote of the difficulty of 'encouraging inexperienced medical staff to do what I know they should,' and 'having to watch bad medical practices and being powerless to comment.'

Time

Use of nursing time

Table 3 shows how nurses consider that their time is allocated to different tasks. Some nurses were concerned to question work priorities and whether the best use was being made of their time.

Many nurses thought that important activities were often neglected when nurses were too busy. 'Too little time for nursing and general unit meetings to discuss individual patients with social worker and doctors.' 'Not enough time for peer group support or senior to junior. This is not felt to be of importance at Brompton, i.e. it is felt more important to send nurses to medical lectures rather than keep them on the ward and make time for discussion.' 'Not time to clean bed space thoroughly for new patient.' 'Difficult to find time to do everything I would like, especially teaching.' 'I wish there was more time to sit and talk with all the parents, answer their questions and be able to support them more.' A few nurses said there was almost no play therapy, and if PICU patients were well enough to play their nurse was too busy sharing other patients. Some nurses thought there was too much routine observation or that their time was misused and certain tasks could be delegated to technical, auxiliary or domestic staff.

Too little time

While peaks and troughs used to be a problem in intensive care, nurses now miss the advantages of occasional slower times; 'we need them to unwind and catch up with other work.' 'The ventilators and IVacs have weeks of dirt in them but no one has time to clean them properly.' 'We've had no time to go to meetings lately.' 'Recent shortages have sent stress rates soaring.' Table 5 shows that nursing cover is considered inadequate.

Instead of agency nurses or a nursing pool, Brompton Hospital nurses, are used to fill gaps caused by staff shortage and sickness, so putting ever increasing pressure on the dwindling number of nurses. Nurses complain about having to work many extra hours by missing breaks and staying on after the end of their shift. 'I work such long hours, I have so little time left for myself.' 'I never get off on time as promised, usually too exhausted and totally depleted, mentally and physically. They shouldn't ring you up when you are on sick leave to ask when you will be back.' Some nurses felt 'blackmailed into working extra shifts'; others refused, although

tempted by the pay, because, 'I feel it would increase the risk of "burn out" and possibly put patients at risk.' (Table 30)

Another main complaint was being sent to cover other wards. (Table 6a) 'If it's your turn you go! If you refuse, someone else has to take your place and bad feeling can occur.' Paediatric nurses disliked working on adult wards and felt the adults' nurses did not like caring for children. 'Nurses from Rose are sent to PICU to help and other nurses are sent to Rose to replace them. The relief nurses may not have worked with children or in Rose which is more of a hindrance than a help.' 'Nursing officers move nurses from Rose when we are very busy, because they don't understand that babies need far more nursing care and time than adult patients do.' 'How will we be able to use the Nursing Process if we are so short staffed?'

Effects of time on nurses' feeling about work

Table 8 poses the question of what is the 'right' pace of work. Nurses may feel that they should expect and not complain about rush in a busy unit. One nurse who ticked 'just right' also wrote, 'Basically it depends on how much work load is put onto a nurse. Sometimes nursing more than one patient at a time (in PICU) can be very stressful, tiring and physically and mentally draining - we are not bionic although sometimes it would be very handy to be!'

'When we are short staffed we have to share intubated patients, nurses get tired and tense all too easily and upset when a lot of patients die. Not exactly a good atmosphere, why are all the staff leaving?' 'Worrying when no time to see new staff properly orientated, more tense when trying to do meal reliefs and unit is not well covered. Frustrating if nurses have to cut short their breaks, or leave work late, or miss lectures and courses because not enough nurses.'

'Lack of satisfaction usually due to heavy workload - when I feel I've done nothing properly but rushed to do my best.'

The interests of children

Working with children, watching them recover and return home with their grateful parents were listed as the most satisfying aspects of nursing. The nurses thought the advantages for children at the Brompton Hospital included 'excellent medical staff, excellent care and surgery, and priority given to children over adults requiring surgery.' (Table 4)

Disadvantages for children in a mainly adult hospital included: 'Hospital environment not paediatrics orientated which can be frustrating,' a lack of paediatric knowledge, training and understanding of the special needs of children among many of the staff, a lack of RSCNs, paediatricians and children's trained staff and 'people who are children orientated'. 'They think of them as "mini-adults".'

'General atmosphere too "stiff" not relaxed enough for children.' Children have to walk through an adult ward to get to Rose. 'No outdoor play area.' 'No schoolroom or schooling time for longstay patients.' 'Not enough play therapy, in fact almost none at all!' 'A lack of space for toddlers to crawl and play.' 'It is very wrong not to have facilities on Rose for mums to stay with their child.' 'Parent accommodation is too expensive (it should be free) and more room for dads to stay.' 'There should be a better midwifery cover for newly delivered mums.' 'Parents are not kept fully informed by doctors.'

'Dreadful food on Rose - totally unsuitable for children.' 'Selection of pre-packed milks is poor.' 'Need special food, small ECG stickers, welcoming atmosphere at hospital entrance, posters, toys in every department.' 'Poor choice of equipment and supplies as orders mainly for adults.' 'Specialised stores can be difficult to obtain.' 'Too much blood taken as labs not equipped to deal with children.' 'A lot of departments fail to appreciate special needs of children, e.g. supplies, theatre, (e.g. keeping nonbypass neonates warm) angio, echo, xray.'

'It is all important to have a completely child centred environment, not only ward and ICU but in all departments. Very little is done to make these areas more appealing/reassuring for children.' 'The most difficult thing is taking unprepared children to theatre especially when their parents are not allowed to go with them, and not being able to follow children through before surgery and afterwards in PICU. No continuity of care.'

Inservice learning

'I like working on PICU but have to leave as there is no promotion available. They will not second people to do courses and there is not much teaching. I have to move to a health authority that runs the post-enrollment courses. There is nothing to encourage me to stay on the unit.'

At every level the non-course nurses felt there was not enough or no chance to learn about changes in nursing practice, cardio-thoracic conditions, management and administration, personal skills or teaching other nurses. (Tables 9 and 26) While bedside teaching was usually the most helpful, correction in front of parents, 'can make a nurse lose confidence rapidly and cause embarrassment' although this may occasionally be necessary for the child's safety. 'This can be done in a tactful way', but 'some nurses take great delight in showing a fellow nurse up,' instead of 'trying not to let parents know as this would make them worry about competence of the nurse.'(Table 26)

Only two kinds of formal training were thought not to be useful: ward rotation should not be enforced, only arranged on nurses' request, and attending out-patients was not useful 'when you only go to help'.(Table 9) Although there were many opportunities available to study, there was often no time to attend, and sometimes no encouragement. 'My application for paediatric society conference study leave refused, "didn't meet the right criteria".' 'Considering that the Brompton is a "fast-moving" hospital I think that the nurses are left behind.' There is little or no nursing research. Considering the amount of medical research it may be a good thing if we did some.'

Nurses had mixed feelings about their work. While some aspects were challenging and exciting, the same nurses found too that 'no use is made of my knowledge', 'there's no opportunity for mental stimulation.' 'Not enough encouragement for staff to share their knowledge in teaching sessions.'

There was some disharmony between groups of nurses which more inservice courses might relieve. Some SENs were thought to be 'too laid-back' but the SENs were unhappy about not being able to have any inservice training. 'Only RSCNs seem to be given the opportunity to learn/practise management.' 'Many SENs (particularly permanent) are hostile and aggressive, almost as if they feel threatened. Very off-putting when you start. Many RSCNs feel that the only people who should nurse children are RSCNs, so the working atmosphere is completely undesirable. Both groups of nurses require counselling as the atmosphere they make is tiring and difficult to work in, teamwork is totally non-existent.'

Suggestions

Although these suggestions require funds, they could be regarded as a necessary investment. They would encourage a more positive use of nurses' ideas and experience, reaping many benefits and enhancing the quality of patient care. They would improve staff morale. They would prevent the present waste of money, resources and good will incurred when nurses leave the hospital because of dissatisfaction with their working conditions.

Nursing time could be used in different ways if:

1. More technicians are employed to clean, maintain and mend equipment, and ensure it is available when needed.
2. More auxiliary nurses and domestic staff are employed to clean and prepare beds and to organise supplies, stock-taking and general housekeeping.
3. More administrative staff are used, for example to arrange patients' transport.

It may be possible to improve nurses' pay and to attract more nurses to work at the Brompton Hospital by creating nursing posts with part time special responsibilities at a higher rate of pay. This could be done in several ways if:

4. Nursing assistance is written into medical research protocols and fund applications.
5. Nursing research projects are designed and funds applied for, so that nurses could supplement their income by doing part time research on a higher salary.
6. Research projects could be designed to help to improve the nursing practice and satisfaction in the hospital, 1) by giving immediate practical help to nurses, 2) by identifying and working towards improvements.

For example:

A permanent nurse counsellor could arrange a course in, say, the care of the dying child, researching the experiences of nurses and patients, evaluating practice, and while supporting nurses in their work, helping them to channel their reactions and ideas into practical ways of reducing avoidable distress, and then evaluating changes in care.

Similar research could be undertaken into: the effects of intensive care equipment and procedures on babies and children; therapeutic play programmes, or designing information and play equipment about cardio-thoracic conditions and treatment; children and pain; treatment of feeding difficulties in cardiac patients.

At present, when nurses do this work in their spare time they are seldom acknowledged or rewarded and the hospital seldom benefits from the results. Time, resources and funds (which could be raised) need to be provided.

7. If more part time nurses, for example, in a 10-3 shift for nurses with young children, and a part time creche were provided, then full time staff could be released for inservice training and meetings. One way to attract experienced nurses to return part time would be to open posts of special responsibility. For example, to put a part time nurse in charge of sorting out problems in supplies systems, or faulty equipment, which may mean negotiating with other hospital departments.
8. The nurses have many practical ideas about better practice. Small working groups could be set up with a budget and a nurse or administrator with sufficient authority to ensure that decisions are implemented. These groups could work with other departments to raise paediatric standards of care. For example: a catering group to plan meals and snack arrangements for children (and for PICU staff); a group to renovate the children's echocardiography area; to plan a children's xray room; to plan paediatric equipment and furnishings in the ECG department.
9. If nurses could be released for regular meetings, there could be a nurses' journal club, or child case study sessions which would give all nurses experience in talking to small groups. Nurses could be paid for organising inservice training sessions, for making sure that journals are available in PICU and Rose or for arranging information boards of interesting articles and news cuttings. Many nurses spend much time teaching, for example when new nurses 'shadow' them; they could be paid and trained for this extra work.
10. Pressure on nurses could be relieved if, at least for some of the time, senior sisters could be supernumerary, instead of trying to fulfil PR and administration commitments at the same time as supporting the nurses.
11. PICU nurses often need one extra nurse who would move around the unit to help the busiest nurse. This could be combined with teaching.
12. PICU and Rose Gallery could each have a clinical nurse teacher.
13. A clinical nurse specialist could be appointed, experienced in cardiothoracic paediatric care, who would also advise on family centred care.
14. A paediatric nursing pool could be created, with pay at enhanced rates. Pool nurses could be used instead of moving nurses from Rose or PICU.
15. Self-financing study days could be organised, and nurses could be paid for helping to organise and to teach at them. This may attract new nurses.
16. Nurses could be encouraged to attend conferences and courses and to present reports about these to nurse meetings.
17. Ways of helping nurses with travel costs, and of improving nurses' accommodation and car parking, also more flexible shift and holiday times could be urgently considered. Several nurses wanted a social club for hospital staff.
18. Nurses could be paid and given time and recognition for organising some of these suggestions.

NURSING SATISFACTION STUDY APPENDIX

Table 1. Nurses who took part in the study

Questionnaires were returned by
 7 sisters/charge nurse, 13 RNs, 18 ENs, 2 NNEB, 12 course nurses,
 3 auxiliary nurses. 3 nurses did not specify a grade.

26 nurses worked mainly on P.I.C.U. and 17 mainly on Rose Gallery.
 13 did not specify an area. Course nurses work in both areas.

48 nurses had been at the Brompton for more than 6 months, and
 9 (all course nurses) for less than 6 months.

Table 2. Priorities in routine

10 nurses thought ward routine should be fitted mainly around nursing tasks.

0 nurse thought ward routine should be fitted around the medical duties

33 nurses thought ward routine should be fitted around the patient's day (such as not being interrupted unless in an emergency).

15 nurses thought that nursing, medical and/or patient's routines were interdependent or equally important or that shifts should be flexible and based 'on teamwork' or on 'the patients' and families' total well-being.'
 (Total number of replies 58 and of non-replies 0)

Table 3. Nursing time allocation

7. Do you think that the time you spend on these activities is

	too much	about right	too little
(total number of ticks meaning 'yes' for each column)			
observations and technical nursing	17	30	10
administrative work	11	31	9
talking and playing with children,)			
washing, feeding and dresssing them,)	0	6	51
play therapy about conditions and treatment)			
teaching and talking to parents	0	12	46
cleaning and tidying	17	29	11
discussing work with colleagues and)			
sharing in nursing decisions)	0	12	46
teaching new nurses	0	21	34

Table 4. Children in a mainly adult hospital

As the Brompton is mainly an adult hospital,
 8 nurses felt children benefitted by being in a small section
 40 nurses thought children missed out on some aspects of child-centred care
 10 nurses thought there were both advantages and disadvantages for children
 (58:0)

Table 5. Nursing cover

Do you think the nursing cover is usually

	enough	too much	too little
a) on PICU (44:14)	8	0	36
b) on Rose Gallery (33:25)	7	1	25

Many nurses answered only for the ward they worked in.
19 nurses thought cover was enough by day but not at night.

Table 6. Working conditions

On the whole, how much control do you think you have over your working conditions?

Nurses were asked to grade 15 aspects of work: a) comfort of uniform, b) attractive design of uniform, c) work rotas, d) last minute changes in duty rotas, e) change room facilities, f) space for outdoor clothes, g) safe place for valuables, h) being sent to cover another ward, i) comfortable place for nurses to relax, j) staff canteen - quality of food, k) nursing management, l) staff counselling and support service, m) concern for you as an individual, n) your own working methods, (such as how you change a nappy), o) allowance for your needs (such as when you feel tired or unwell or upset).

As an overall total:

6 nurses thought they had a lot of control over work conditions
27 had a reasonable amount
25 nurses thought they had too little control
(58:0)

Some nurses ticked an alternative 'not important to me' which lowered their score.

For this report, only two items have been analysed in detail, h and m.

Table 6a. Being sent to cover another ward

3 nurses thought they had a lot of control about being sent to cover another ward
6 nurses marked a reasonable amount.
35 nurses marked too little.
14 (mainly course nurses who are not moved to other wards) said this did not concern them.
(58:0)

Table 6b. On concern for the nurse as an individual

1 nurse marked that she thought there was a lot of concern for her
23 nurses marked a reasonable amount.
30 nurses marked that there was too little concern for them.
(54:0)

Table 7. Ward atmosphere

How do you think of the ward as a place to work in?

a) friendly, b) rather tense, c) interesting, d) satisfying.

33 nurses thought the ward was usually a pleasant place to work in.

20 thought it was sometimes so.

5 nurses thought it was rarely satisfying and often tense

(58:0)

Table 8. Pace of work

Do you think the pace of nursing work is just right, too rushed, too slow, too varied between fast and slow?

6 nurses thought the pace was usually about right,

34 nurses thought the pace was sometimes right but often too rushed

9 nurses thought the pace was rarely right, usually too rushed.

(49:9)

Table 9. Nurse inservice training

11 inservice training items were listed: a) one or two study days annually, b) visits to other hospitals, c) weekly meeting on a set topic, d) rotation of nurses between Rose Gallery and PICU, e) attending a conference, f) talks on medical conditions and treatments, g) talks on nursing methods and research, h) regular attendance at paediatric out-patient clinics, i) talks on emotional support for families, j) monthly meetings, k) support groups for nurses.

57 nurses thought more should be arranged of most kinds of training.

0 nurse thought that on the whole enough training was arranged.

0 nurse thought too much time was spent on training.

(57:1)

Table 10. Nursing qualities

What sort of qualities in a nurse working at your level do you think are important and which of these qualities do you feel that you are most expected to have or to use?

25 qualities were listed and for this report they have been grouped into three broad categories:

Table 10a. General qualities

which would be useful in almost any work:

patience, energy, politeness, flexibility, punctuality.

30 nurses thought all these qualities were very important

28 nurses thought most of these qualities were very important

(58:0)

21 nurses thought they were expected to use general qualities a great deal

11 thought they were expected to use them quite a lot.

(34:24)

Table 10b. Personal qualities

concerned with caring for others:

imagination, sympathy, gentleness, kindness, tact, friendliness to other nurses, friendliness to doctors, liking children, friendliness to parents, loyalty to other nurses.

28 nurses thought that all the personal qualities were very important

30 thought that many of these qualities were very important

(58:0)

3 nurses thought they were expected to have the personal qualities a great deal

23 nurses thought they were expected to have them quite a lot

7 nurses thought they were not expected to have them much.

(33:25)

Table 10c. Organisation skills

administrative skill, technical expertise, management skill, ability to handle people firmly, ability to negotiate with doctors and with senior nurses, firmness with parents, confidence in talking to groups of people, ability to give clear reports, aiming for very high standards.

6 nurses thought these qualities were very important

41 nurses thought many of the qualities were very important

11 nurses thought that a few were very important.

(58:0)

1 nurse felt expected to use these qualities a great deal

12 nurses thought they were expected to use them quite a lot.

20 nurses thought they were not expected to have them much.

(33:25)

Table 11. Ward rounds

How much would you like to be involved in ward rounds?

a) to report on patients, b) discuss treatment, c) to learn about medical conditions, d) to learn about patients' treatment.

45 nurses wanted to be more involved

9 nurses already felt sufficiently involved

2 nurses wanted to be less involved

(56:2)

Table 12a. Positive nursing view of ward rounds

How do you think ward rounds tend to be seen by nurses, parents and children? - a) as a vital part of medical care, b) as interesting and a welcome event, c) as a helpful time to share information.

2 nurses thought ward rounds were seen as a positive benefit

18 nurses thought they were seen as moderately useful

37 nurses thought they were seen as of little help

(57:1)

Table 12b. Negative nursing view of ward rounds

Do you think ward rounds tend to be seen by nurses, parents and children as b) too long and disruptive and d) boring?

1 nurse thought ward rounds generally had a very negative impact
6 nurses thought they had a moderately negative impact
39 nurses thought they were a little disruptive and boring
11 nurses did not think they were disruptive or boring
(57:1)

Table 13. Information to parents

Do you think that on the whole the information given to parents is enough?
- a) on their child's medical condition, b) progress, c) treatment (drugs, surgery, equipment, other procedures), d) on how parents can help to care for their child in hospital, and e) after discharge.

0 nurses thought parents were told too much
12 nurses thought parents were told enough
44 nurses thought parents were told too little
(56:2)

Table 14. Involving parents in decisions

Do you think parents share in making decisions about their child?

0 nurses thought parents shared too much in making decisions
21 nurses thought they shared enough
34 nurses thought parents had too little share in making decisions
(55:3)

Table 15. Informing children

15. Do you think when children are old enough to understand they are told enough about a) their medical condition, b) what their treatment will involve, c) how they are likely to feel during procedures, d) how they can help themselves to cope and relax?

9 nurses thought that children were usually well informed
38 nurses thought they were sometimes informed
5 nurses thought children were rarely informed
(52:6)

Care when a child dies

These are difficult questions to ask and to answer, not very suitable for the medium of a questionnaire. The comments are more informative than these tables and they will be given more fully in a later report. Many items were left unanswered and therefore show a low score, which seems more likely to indicate uncertainty than satisfaction.

Table 16. When a child is dying or has died, what do you tend to do with his/her parents? (total number of ticks)

a) try to leave them alone	19
b) try to talk about ordinary or cheerful things	3
c) encourage them to talk about their sadness	37
d) just sit with them quietly	38
e) if you feel upset, share your distress with them	34
f) encourage them to cry	26
g) touch them comfortingly	48
h) talk about practical arrangements	24

Table 17. Would you like to show more sympathy?

37	nurses said yes
16	nurses said no
5	nurses gave no answer

Of the nurses who said, 'Yes',

26	held back because they were not sure how to help
21	were worried that they might upset the family
1	nurse felt unsure about what other nurses would think of her behaviour

Table 18. Difficulties when an older child is dying

16	nurses felt not sure how to help
17	nurses worried that they might upset him/her
1	nurse was not sure what other nurses would think of her behaviour
20	nurses felt guilty or had a sense of failure

Table 19. Do you think there are enough facilities and help for parents whose child has died?

	enough is offered	more should be arranged
a) a quiet private place	23	31
b) someone to sit with them	17	33
c) help with finding friends/relatives	32	16
d) practical help	26	20
e) financial help	15	19

Table 20. Talking to parents

Do you find that it is difficult to talk to parents when:

	often	sometimes	never
a) you do not know how much they have been told about their child's condition and prognosis	23	33	1
b) you are very busy with other nursing duties	21	30	6
c) you know more about a gloomy prognosis than the parents have been told	20	32	5
d) you change duties so that you do not get time to know the parents	7	35	13
e) you feel that the parents are aggressive/difficult	3	46	8
f) you have not been told enough about changes in the patient's plan of care	11	36	7
g) you feel that you do not have enough knowledge to answer the parents' questions	9	41	6
h) different doctors seem to be giving different accounts	22	27	6

Table 21a. Support for nurses with a personal problem affecting their work

If you have a personal problem which is affecting your work, what kind of support would you expect?

	support & understanding	a little sympathy	a brief talk	no help
a) from nursing colleagues, more senior and more junior nurses	20	20	14	0
b) nurse teacher	26	4	10	9
c) nurse administrators	16	8	11	17
d) other members of hospital staff	4	10	3	34
e) friend/relative outside hospital	42	11	1	0
f) nurses support group	19	5	7	19

Table 21b. Support for nurses with a work problem

If you are finding something particularly difficult about your work what kind of support would you expect?

	high levels of support	a brief talk	no help
a) from nursing colleagues, more senior and more junior nurses	44	13	0
b) nurse teacher	17	28	5
c) nurse administrator	6	25	20
d) other members of hospital staff	9	14	30

Table 22. Thoughts about work when off duty

When you are off duty do you think about work? -

a) look forward to going back on duty, b) think about the children who recover and thrive, e) remember the good times (at work), or c) worry about children whose treatment is not successful, d) about the family of a child who has died, f) feel anxious about problems at work.

5 nurses usually had positive thoughts about work when off duty

43 nurses often felt positive

6 hardly ever had positive thoughts about work when off duty.

(54:4)

Table 23. Staff social activities

Do you think that informal social get-togethers between all kinds and levels of staff a) make for a friendly work atmosphere, b) can undermine discipline, c) are a waste of time, d) are enjoyable, e) improve work relationships?

19 nurses thought that social occasions were usually beneficial

28 nurses thought there were mixed benefits and disadvantages

9 nurses thought there were mainly disadvantages

(56:2)

Table 24. Sick leave

Table 24a. Have you ever wanted to take time off sick because of the pressures of work?

20 nurses never had wanted to take time off because of pressure

33 nurses had sometimes wanted to

5 nurses often wanted to take time off because of pressures of work.

(58:0)

Table 24b. In the last 6 months have you taken time off sick because of the pressures of work?

3 nurses said yes

35 nurses said no

20 nurses did not answer.

Table 25. Study

Do you think nurses should be given more time and opportunity for study? -

a) reading journals, b) discussing work, c) introducing new methods, d) research

53 nurses thought more time was needed

3 nurses thought enough time was given

0 nurses thought too much time was given for study.

(56:2)

Table 26. Teaching methods

Which do you consider are effective teaching methods?

- 54 nurses thought that three methods were helpful:
 - waiting to talk privately about a mistake
 - setting the right example
 - working through a problem with a nurse to see why it is happening
- 25 of these nurses also thought a fourth method was helpful:
 - self-directed learning
- 4 nurses thought that a fifth method could be helpful:
 - correcting a mistake at once, although this may mean making parents aware of another nurse's mistake.

Table 27. Reaction to patients' problems

How do you usually react to some of the patients' problems?

- a) children on ventilators, b) surgical wounds, c) cut downs, d) drips, IV
- e) naso gastric tubes. f) cancelled surgery, g) endotracheal suction, h)
- children seeming in pain, i) giving children injections, j) angry or upset
- parents, k) cardiac arrests, l) child going for very high risk surgery.

On the whole:

- 2 nurses often felt upset
 - 52 nurses sometimes felt upset
 - 2 nurses rarely felt upset about patients' problems.
- (56:2)

Table 28. Other hospital staff

How helpful do you usually find other members of staff?

- a) technicians, b) porters, c) SHOs. d) registrars, e) consultants,
- f) social workers, g) chaplain, h) domestic staff, i) secretaries.

- 2 nurses found other staff very helpful
 - 33 nurses found them quite helpful
 - 21 nurses found other staff to be sometimes unhelpful
- (56:2)

Nurses added, that ward clerks, pharmacy and physiotherapists were helpful.

Table 29a. Hospital authorities' values concerning personal nursing care

How much do you think the hospital authorities value these aspects of nursing at Prompton Hospital?

- a) family centred care, d) informality and friendliness, e) flexible care of individuals.

- 2 nurses thought these aspects were valued a lot (too much).
 - 36 nurses thought they were valued enough.
 - 15 nurses thought they were valued too little.
- (53:5)

Table 29b. Hospital authorities' values concerning technical nursing care

How much do you think the hospital authorities value these aspects of nursing at the Brompton Hospital?

b) highly skilled thoracic-cardiac technique, c) efficiency and high workload, f) support for medical research, g) support for advances in surgery and treatment.

23 nurses thought these aspects were valued a lot (too much)

24 nurses thought they were valued enough

1 nurse thought they were valued too little

(48:10)

Table 30. Agency or overtime shifts

How many agency/overtime shifts have you worked in the past six weeks?

12 nurses said they had worked some agency/overtime shifts at the Brompton.

34 nurses said they had not worked any extra shifts at Brompton Hospital.
(46:12)

10 nurses said they had worked shifts at another hospital.

35 nurses said they had worked no shifts at another hospital.

(45:13)

This table does not show unofficial overtime such as leaving work late and missing breaks.