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Summary

Traditionally, children have been identified as incompetent to consent to health treatment. In the mid-1980s English law changed. Although their welfare rights are generally accepted, their autonomy rights are tenuous, and disputed on the grounds of their incompetence. This paper examines children's competence, firstly in the current context of children's international and legal rights, and then through reviewing the history of their presumed incompetence. Growing evidence of children's competence is reported, drawing on examples from a recent empirical study of children having surgery in English hospitals. The advantages and problems of respecting children's competence are considered.

One hundred and twenty orthopaedic patients aged 8 to 15 years, 54 boys and 66 girls, were interviewed in 4 hospitals: Westminster Children's; the Hospital for Sick Children at Great Ormond Street; the Royal National Orthopaedic at Stanmore, and the Royal Liverpool Children's Alder Hey. The age range is shown in table I.

The children[i] were having elective surgery for reasons shown in table II. The patients were already well informed, on average they had had 4 operations and 6 hospital admissions. The 6 accidents had occurred years earlier, leaving serious defects. Fifty eight patients had chronic disorders besides the specific problem being treated. Some disorders, such as cerebral palsy, were linked to the condition requiring surgery, others, such as diabetes, entailed separate but partly relevant hospital experience. There was a wide range of intelligence, and 8 children attended special schools for learning difficulties.

One hundred and four mothers and 32 fathers, were also interviewed (for computer entries, couples' replies were counted as 1 entry). The 70 hospital professionals were: 6 surgeons, 10 physicians, 15 sisters and senior nurses, 6 ward nurses, 4 therapists, 5 social workers, 2 chaplains, 12 teachers, 4 play specialists, 5 psychologists and a child psychiatrist.

PROCEDURE

After the project had been approved by the 4 Ethics Committees, 117 families were contacted in the wards after admission for surgery, and 3 were first interviewed at home. Nurses advised us when they thought we should avoid certain vulnerable patients. The interviewers (PA and JS) described the study and asked for the parents' and patients' consent to take part. They were given a leaflet explaining the study with time, if they wished, to consider whether to consent. They were told that the study was based 'at a research unit, not at the hospital' and 'when we use what you say in a report, we'll make sure that no one will know that you said it, and we'll give you a different name'. Some patients said they preferred fame to anonymity, so the protection of confidentiality was explained. They were assured that they could refuse to take part, and if they took part but did not like a question they could say 'pass'; they could also pause, or stop the interview at any time. Interviews were fitted around patients' commitments, such as school lessons, viewing soap operas and visiting Xray.

Children and parents chose whether to be interviewed separately or together. Their choice and sharing of joint interviews illustrated varying ways of responding to the child's growing independence. After surgery, 85 interviews were held in hospital and 35 at home. Sixty two children were questioned a third time, on average 31 weeks after their operation. The professionals were interviewed in the hospitals. Interviews lasted from 10 minutes to 2 hours, with an average of 30 minutes.

The four semi-structured interviews with children and parents were based on a schedule of 175 questions, but usually expanded into conversations. When asked, 'Why have you come into hospital?', or 'How have you been getting on since I saw you?' some children would give a detailed account which answered many of the questions, leaving a few to be filled towards the end of the interview. Other children tended to reply briefly to formal questions. Most interviewees added details that especially concerned them.

The families' interviews covered: aspects of children's personal and medical history; their hopes and fears about treatment; when and how they thought that they were, and should be informed and involved in treatment decisions. Later interviews reviewed peri-operative and post-discharge experiences and preferences, and further views on how the families shared and negotiated decisions.

The professionals were asked 10 questions mainly about: the ages at which children can be informed and involved in making decisions; ways of defining and assessing children's understanding; and cases of children refusing surgery.

One third of all the interviews were tape-recorded and transcribed, and all interviewees were sent a brief report of the project findings.

The context of rights

Children's rights can be divided into three kinds.(Franklin 1986) Firstly, there are rights to resources such as education and health care. Secondly, there are rights to protection from harm and abuse. These welfare rights are enshrined in the United Nations Convention on the Rights of the Child (1989) which has been ratified by Governments around the world. Such `rights' can as easily be discussed under the rubric of children's needs, interests or welfare. State authorities tend to be remiss in actually providing many of the resources and protections detailed in the Convention (the Children's Rights Development Unit in London compiles lengthy reports detailing the severe limitations and restrictions on children's welfare rights in the UK). Yet the principle that children are entitled to such resources is relatively widely accepted, as shown by official international support for the Convention.

However, the third form of rights for children, autonomy rights, is generally more contested. The modern concept of `rights' is only about 400 years old, when the first and basic right concerned autonomy, as later elaborated by philosophers such as Locke (1924) in the seventeenth and Kant (1948) in the eighteenth century. They justified respect for autonomy on the grounds that man is a rational being and no one has the right to interfere with his personal decisions. Women and children were specifically excluded. Later, Mill (1859) acknowledged that adults are not always wise, but he advocated liberty as the greatest good and, for adults, set autonomy above welfare.

Autonomy concerns the right to take charge of one's own life, to make personal decisions without interference, the right to choose, and to give or withhold consent.

Consent has an impact on all other rights. Consent is about selecting options, negotiating them, and accepting or rejecting them. It is about deciding one's own best interests and preferences. Consent determines whether children can decide which rights they prefer to have, or whether adults choose for them.

Arguments against respecting children's competence, collected during our research interviews (in the surgery study reported below) and also from many conferences and seminars at which the research has been presented, may be summarised as these comments about children:

* they are too ignorant or foolish to know their own best interests, so that these must be decided for them by competent persons;
* they are too weak and vulnerable to exercise their own rights;
* they are not capable of taking a full, adult part in public life, even if this was allowed to them;
* it is cruel to expect them to take charge of their own life, and to burden them with responsibility and anxiety, they would feel guilty and confused;
* if they are sensible and know their own best interests, they understand that it is best for others to decide for them, and they are obedient and compliant;
* the ones who protest against the status quo just prove how foolish and irresponsible they can be, if not firmly controlled.

Perhaps these arguments sound familiar. They were used less than 100 years ago about another social group - women, as well about as black people and other `minority' groups. These arguments overlook two crucial questions: Whose interests are the discussants really talking about? And what is the evidence to support their beliefs?

When re-read in terms of men discussing women, or colonialists discussing native populations, conflicts of interests, and the speakers' functionalist assumptions that the interests of the powerful serve everyone's needs, become apparent. Baker Miller's analysis (1976) of these conflicts is highly relevant. One of our interviewee's, a hospital chaplain and former headmaster drew attention to a major issue within assessments of competence: the power of adults over children's lives, and the threat to adults' convenience, comfort, dignity and hold over resources which children's autonomy can present. He said:

> But are you going to lay on children the weight of their future? Perhaps let them make a decision that could lead to their death? These are impossible questions, but hospital staff have to find the answers. Am I big enough to say, `Whatever you choose will be valued, even if you decide against the tide; okay, you've made that decision, I'll do all I can to support you, and we'll go forward together'? It's such a big step for the adult to surrender power to the child.

Freedom to exercise rights

The Nuremberg Code, drawn up in 1947 after Nazi medical atrocities were reviewed during the Nuremberg trials, assumes that the ordinary person can have `sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision'. The Code mainly emphasises the third key element in autonomous decisions, non-coercion. It begins: `The voluntary consent of the human subject is absolutely essential.... free power of choice, without the intervention of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion.' People making or sharing in decisions about major medical treatment are constrained by their illness or disability, their fear, anguish and uncertainty about likely outcomes, and their relative ignorance. When facing dilemmas, as MacIntyre (1981) has argued, they are torn between making, not a correct or incorrect decision, but a choice between options which are each offer hope of benefit yet also harm and the loss of benefits held in the other options. Even so, codes of ethical practice veto avoidable coercions, such as pressure or misinformation from health professionals which unduly influence a decision. When assessing children's competence, avoidable pressures, and possible conflicts of interests between the child and the caring adults, have to be considered. A major coercion is the common assumption that children are incompetent and unable to make `enlightened decisions'.

The right to physical and mental integrity is the basis of Anglo-American law. `Every human being of adult years and sound mind has the right to determine what shall be done with his own body', as Judge Cardozo summarised in the sexist and ageist terms of the time.(Schloendorff v. Society of New York Hospitals 211 NY 125, 1914) Autonomy rights can conflict with welfare rights as when people refuse medical treatment or education intended to benefit them. However, the rights also complement one another, as when education respects and nurtures the child's autonomy, and when health care is provided with the patient's willing cooperation, instead of being imposed on the resisting patient.

The UN Convention enshrines the rights of competent children to influence decisions about their care.

> States shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child will be given due weight in accordance with the age and maturity of the child. (Convention 12.1)

> For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial or administrative proceedings affecting the child, either directly, or through a representative or an appropriate body ... (12.2)

> The child shall have the right to freedom of expression: this right shall include freedom to seek, receive and impart information and ideas of all kinds ... (13.1)

The Convention acknowledges that respect for children's autonomy varies with their legal status in each nation state.

Children's rights in law

Legal views of children's competence to consent are changing in many countries from an emphasis on a stated age of consent to interest in individual ability or competence. During this century, the age when women could begin to vote has fallen in the UK from never, to 30, to 21 and now 18 years. Since 1962, Canada has allowed minors from 14 years upwards rights of consent to medical treatment. Scottish law allows quite extensive common law rights to girls at 12 and to boys at 14, in contrast to the English ages of 14 for boys and variously 12, 14 or 16 for girls, (Kennedy 1988:82) who, until

1929, could marry at 12. Many laws state ages from 0- to 21-years when children become entitled to certain adult rights. For instance at 12 years of age you can buy a pet in England. (Children's Legal Centre, 1991)

By 1991, three American states had a legal age of consent of 19 years, and the others had 18 years, (Robinson 1991) but many states allow certain minors the right to consent to treatment without their parents' knowledge. These exceptions depend on the required treatment, not the child's maturity; they include treatment for contraception and abortion, for alcohol and drug dependence and psychiatric disorders. The exceptions may even be said to be defined by immaturity, in that they tend to concern deviant or risk-taking behaviour. The legal exceptions are pragmatic, to enable young people to seek help and treatment which their parents might veto. Yet the questions remain: If `deviant' minors can consent to abortion, why cannot their possibly more mature and prudent peers consent to appendectomy? An arbitrary `age of consent' raises the anomaly of the magic birthday. How can someone be an incompetent infant one day, but a mature adult the next?

Children's rights in English law were reviewed during the Gillick case. (Gillick v. West Norfolk & Wisbech AHA [1985] 3 All ER). Mrs Gillick took her health authority to court in the mid-1980s. She wanted the court to rule that children under 16 in general, and her ten children in particular, could not obtain medical treatment without their parents' knowledge and consent. She was mainly concerned to stop children's access to treatment and advice about contraception.

In 1969, the Family Law Reform Act stated that children aged 16 and 17 years can give effective consent to medical treatment; their parents' consent is therefore not necessary. The Act failed to state that children under 16 cannot give legally effective consent. Mrs Gillick wanted the court to make a clear ruling that minors under 16 cannot give consent.

The case went through several hearings and some judges agreed with Mrs Gillick. However, the Law Lords finally ruled that English law is concerned with each child's competence, rather than with their age. Children of any age may consent, which includes the option to refuse, when they are competent to do so. Competence entails understanding and wisdom - being able `fully to understand what is proposed', and also `having sufficient discretion to [be able] to make a wise choice in [their] best interests'.

The 1989 Children Act enshrines this view, stating that children may give consent `if they have sufficient understanding to make informed decisions'. The Act repeatedly states that in decision making, `the child's wishes and feelings' should be ascertained, and states that a competent child may `refuse a medical or psychiatric examination'. The law opens the way for children to have the right to be consulted seriously about all decisions which personally affect them: decisions about medical treatment, surgery and health care, residence and contact with their parents, their education, religion, and other decisions affecting their welfare.

The Gillick case illustrates contrasts between former and present day beliefs about children. A century ago, they were seen mainly as their father's property. People under 21 years of age were legally `infants', literally meaning without speech; they had to depend on adults to decide and speak on their behalf. However, the Gillick ruling emphasised that, today, parents only have rights over their children in so far as these enable parents to fulfil their responsibility to care for the child. And these `dwindling rights', as Lord Denning described them, yield to the child's growing competence. (Hewer v. Brant 1970). There is no sudden cut-off point at 16 or 18. Children can share in making decisions about their care and their lives as soon as they are competent to do so. Recent cases in the High Court have challenged this ruling, (In re R [1991] 3 WLR 592; in re W [1992] 3 WLR 758-82) yet a broad trend of respecting younger children's decisions can be traced in English law.

Yet should children have legal autonomy rights? The crucial question is whether children can make competent decisions. Competence has two main aspects: the ability to understand the relevant information, and the wisdom to evaluate knowledge and to make a decision in one's own best interests. These two threads of understanding and wisdom, cognitive and moral development, run through all discussions of competence. In law, it is generally accepted that adults' personal liberty, however self-destructive, takes precedence over their welfare; for children, their adult-defined welfare predominates over their autonomous choice. Another difference is that adults are assumed to be competent unless proved otherwise, but children are assumed to be incompetent unless, in English law, an assessor, such as the doctor treating the child, decides that they are competent.

The history of children's incompetence

Human relations in Europe during the feudal age of fealty and mutual obligation shifted during the Enlightenment to more impersonal relations of contract and consent.(Goodey 1991) Competence became an increasingly crucial issue, expanding from legal disputes over property rights, to many other areas of life; over the centuries the status of legal competence has gradually been extended to a wider range of adults. Anthropologists show how, since competence is hard to define positively, it is reinforced negatively by defining certain groups (such as children) incompetent, so that other groups (such as adults) can comfortably assume their own competence by virtue of their status as members of that group.(Young 1990:65-82) Educationalists, psychologists, lawyers, doctors and other experts appointed to advise society on children's abilities have assumed and `proved' children's incompetence.

Scientific evidence relating to children's competence has been constrained by powerful traditions. `Hard' science follows models of animal research and concentrates on investigating children's physical development and behaviour, an approach which ignores children's personal thoughts and feelings in the context of each individual life. Like the law which is built on past precedent, natural science tends to be conservative, (Benton 1977) concentrating on present evidence, the status quo, and assuming that one `correct' scientific analysis is realisable. This approach tends to avoid considering possibilities and alternatives. For example, much psychological research aims to discover what children can achieve unaided, rather than what they might be able to achieve given a little help. Scientists are as deeply affected as anyone else by fashionable beliefs, such as that children are incompetent to give consent. Children's consent to medical research is only recently being respected in ethics guidelines. (British Paediatric Association 1992) By accepting and not questioning common prejudices, partly by default, researchers lend authority to prejudice against children. Researchers' uninterest in children's competence to consent is likely also to have been influenced by the practical convenience of ignoring this issue, which can complicate and at times obstruct researchers' access to child research subjects.

A major aim in research is to discover general laws. Examples such as Harvey's discovery of the circulation of the blood are clearly valuable in understanding and treating children's bodies. General laws are less useful when applied to children's minds; they tend to underestimate children's abilities, motives and informed choices, all important aspects of competence. Instead of being acknowledged as moral agents, children can appear to be blindly driven by their biology, such as when a small boy's love for his mother is seen as an Oedipus complex.

Qualitative research which offers flexible and sensitive methods for investigating children's hope and fears and values is frequently criticised as `soft and biased'. One valuable contribution of qualitative research is reflexivity, examining the researcher's own motives and reactions. Scientific study of babies and children, for example, is

> a venture in self-reflection... Scientists studying babies do not simply measure and calculate, they take part in a debate about the moral status of human life which stretches back through countless centuries of poetry and religious teaching... Scientific observations about babies are more like mirrors which reflect back the preoccupations and visions of those who study them like windows opening directly on to the foundations of the mind. (Bradley 1989:9-10)

So Piaget envisaged the young child as a lonely scientist struggling to solve intellectual problems, isolated from social and emotional ties. Scientists project onto research their own dreams, as when they perceive the human body in terms of clocks, pumps, computers or malleable genes.(Merchant 1989) Adults', including scientists', perceptions of children are inevitably context-bound, partial and disputed.

Piaget believed that children develop through inexorably unfolding cognitive stages, like the physical stages of development which are scarcely affected by external forces. He thought that children can rarely grasp certain concepts before the age of seven or eleven. For example, in repeated experiments, he asked children to point out a spot on a model of three mountains which could not be seen from certain other sites. Children under seven did not solve the puzzle. Piaget then inferred that these children could not appreciate another person's viewpoint and did not have `role-taking skills'. He labelled them as egocentric, (Piaget 1977) which he had originally set out to prove following Freud's theory that the child is narcissistic.(Bradley 1990:86) Piaget concluded that many children think illogically, instead of looking for their own sense and meaning. He also assumed that limitations resided in the child and not in his own research methods. His findings reinforced children's particularly dependent and infantile status at that time in Europe, and their apparent need for very protective adult control. nannies wore nurses uniforms, as if childhood were an illness.

Building on Piaget's theories, Kohlberg (1981) proposed six stages of moral development from trying to please other people to using abstract universal principles. Many adults never reach the highest stage. If these masters were right, there would be little point in trying to involve children in thinking about consent to surgery, because they would be unable to grasp the basic intellectual and moral concepts.

Piaget's work, developed in the 1920s and 1930s, has been refuted. Psychologists find that 3-year olds can solve the abstract mountain puzzle and harder puzzles too, when they are translated into personal terms of naughty boys hiding from policemen.(Donaldson 1978) Experiments with babies have shown that they appear to reason and to link cause and effect in ways which were once thought to be impossible in small children. (Siegal 1991) Detailed observations of 1- and 2-year olds have found their intense empathy with other people, and their moral appreciation of others' approval or distress.(Dunn and Kendrick 1982) It seems that Piaget could not appreciate the child's viewpoint when designing dull, repetitive tests; he then projected his own ego-centrism onto his research subjects. Piaget was so convinced of the young child's egocentricity `shut up in his own ego [and] following his own fantasy' (Piaget 1932:53) that he interpreted all his data to support his theories.

Kohlberg's scheme of moral development has been similarly reassessed by Gilligan (1982). She agrees that many people, mainly women, seldom progress beyond Kohlberg's third stage of helping and pleasing others. At stage four relationships are subordinated to rules, and at stages five and six morality involves reflective understanding of impersonal universal principles and individual rights. Yet Gilligan questions the hierarchy, saying that level three, a personal caring morality, is not inferior but complementary to Kohlberg's level six of abstract principles. Gilligan's insights have been welcomed for recognising the mature morality of many women, thus granting them a new moral status. In so doing, her work also recognises the mature moral understanding of many children.

Erikson (1971) shared Piaget's and Kohlberg's assumption that increasingly isolated autonomy was essential for adolescents' moral development. `In order to become conscious of one's ego, it is necessary to liberate oneself from the thought and will of others.'(Piaget 1932:87) Maturity was therefore seen as a process of growing away from the parents. However, when Apter (1990) interviewed mothers and adolescent daughters, many said to her, `We must be very unusual but we are not growing apart, we're becoming closer'. Apter concluded that the autonomy trajectory does not fit many girls, and possibly many boys. As well as growing in independence, adolescents mature through deepening relationships, fitting Gilligan's concept of a morality based on relationships rather than on rules. Identifying maturity and autonomous self-awareness with shared negotiation and decision-making rather than with lonely, isolated responsibility (as is assumed by many bioethicists) enriches the meaning of competence. Sick and dependent people, who choose to share decisions about treatment with their doctors and relatives, are not necessarily lacking in mental autonomy and competence.

Piaget described his stage theories as real, and directly reflecting `actual psychological activities' in the child's mind. (Piaget 1957:7) Yet theories are only patterns describing experience, whether in their narrow sense as hypotheses tested by research, or in their broad sense of working assumptions. Despite recent understanding of children's early intellectual and moral maturing, out-dated theories continue to dominate professional and public beliefs about childhood. The popularity of developmental theories has outlasted their credibility possibly because they support pedagogic claims to unique and powerful expertise in testing and classifying children, and interpreting between `the child's world' and `the adult world'. For example, the paper `There's a Demon in Your Belly' (Perrin and Gerrity 1981) (`demon' as a misunderstanding of oedema or swelling) purports to show how children grow through the unrelated Piagetian stages, from early `magical belief' in the causes of illness, to `multiple factors' in adolescence. There is no acknowledgement that children tend to believe what adults tell them, that people of all ages have magical beliefs (such as guilt) about illness, and that knowledge dramatically changes through personal experience. The paper reports healthy children's views. It would be more logical to attribute children's misunderstandings not to biological immaturity but to inexperience; young children are like adults handling a foreign language or a new experience with quick-witted inference. Many adults are also confused by medical terms.

Piaget's theories have been used almost as facts on which to found bioethics guidance.(Gaylin and Macklin 1982; Melton, Koocher and Saks 1983; Nicholson 1986; Kopelman and Moskop 1989) A recent example on `incompetents', referring to Piaget's mountain test, stated:

> Role-taking skills are also thought to be necessary to enable a child to consider as potentially valid both a position presented to him or her by the physician and his or her own, different position, so that the alternatives can be weighed against each other. These skills are undergoing substantial development in the 8 to 11 age period, and are often quite well developed by 12 to 14. (Buchanan and Brock 1989:220, quoting Grisso and Vierling 1978)

These authors continue with an elaborate analysis of competent thinking. It is perceived as a set of mechanistic skills, isolated from experience, feeling and the social context. The skills include the ability to concentrate,

> to weigh more than one treatment alternative and set of risks simultaneously (i.e. cognitive complexity), ability to abstract or hypothesise as yet non-existent risks and alternatives, and ability to employ inductive and deductive reasoning... and abstract concepts in problem solving.

It is questionable how expert in the listed skills people need be to qualify as competent, and whether they actually think in this way. The philosophers label young children as `incompetents' because they are supposed to be incapable of `cognitive complexity', to have unstable, transient values, no real concept of `the good', of death, of their future, or their likely future values.

As an institution, childhood is a set of beliefs and practices determining how children are treated and how they respond. In many times and places in the world, after infancy children have not been markedly distinguished from adults.(Aries 1962) People aged 12 years are treated like adults in one society and as helpless dependents in another, or in the same society. Solberg's research with Norwegian twelve year olds shows how the ones whose parents expect them to take on adult responsibilities can do so, but the ones who are treated as immature and irresponsible tend to remain so.(Solberg 1990) The view that all children need special care and protection has only taken hold on the public imagination during the past few centuries, mainly in the Western world. A huge change occurred in Western society during the nineteenth century when children were confined into schools. Formerly streetwise children were denied `socially significant activity', (Schnell 1979) and this probably reduced their `sense of their own value... Whatever the compensation, the school put these children into the servitude of a repressive innocence and ignorance'.(Hendrick 1990:47) The rigid age-banding, and school teachers' claims that children do not learn unless they are formally taught by experts are seldom questioned today. Traditions and conventions combine to reinforce the popular view of children's general incompetence.

Children's competence as understanding

The Gillick ruling raises questions about when children become competent and how competence can be defined and assessed. During 1989-1991, my colleague Jill Siddle and I carried out over 500 in-depth qualitative interviews to examine these questions.

We talked with children aged 8 to 15 years having major surgery in four hospitals in London and Liverpool, and with the adults caring for them.(Alderson 1993) Among our many questions, the two key ones were: When are children old enough to understand the relevant medical information? When are they mature enough to make wise decisions in their best interests? The replies, from the children, their parents and 70 health professionals, covered an age range from early childhood to `never'. Table 1 shows the age spread of the 120 experienced young patients we interviewed. Mean age of boys and girls in the study is calculated on their individual ages, not on age grouping means. On average, they had already had five operations.

Table 1 - Age spread of 54 boys and 66 girls (n=120)

	Age groups			
	8-10 years	11-13 years	14-15 yrs	Mean age
Boys	24.6%	40%	35.4%	12.4yrs
Girls	25.9%	35.2%	38.9%	12.1yr

Table 2 shows the condition which led to their need for surgery.

Table 2 - Reasons for having surgery

Patients (n=120)	Condition
44	Scoliosis
7	Various forms of displaced vertebrae
1	Spinal tumour
10	Congenital dislocation of the hip
9	Perthes
22	Congenital defect or congenital bone disease affecting leg or foot
18	Malformations of hip, leg or foot due to the effects of muscular dystrophy, cerebral palsy, spina bifida, Friedrich's Ataxia or Hurler's syndrome.
6	Post-accident chronic defect
3	Short stature

The 70 health professionals interviewed were: 6 surgeons, 10 physicians, 15 senior nurses and nurse managers, 6 ward nurses, 4 therapists, 5 social workers, 2 chaplains, 12 teachers, 4 play specialists/child life workers, 5 psychologists and one child psychiatrist. They were working mainly with children having orthopaedic and general surgery. We chose orthopaedics as frequently a chronic, seldom life-threatening condition, in order to discover how well children could understand, given time and experience. However, since life-extending decisions are so highly relevant to understanding of children's competence, we also interviewed a few staff working in heart-lung transplant and bone-marrow transplant units. Eight years was chosen as the youngest age when we felt able to ask people to do research interviews, with strange sociologists during the crisis of having surgery. The children's mature responses indicated that we could have included younger age groups. Parts of the interviews dealt with current experiences; other parts covered memories of earlier experiences and thought about the future.

Ages of understanding

We did not attempt to test the young patients on their levels of knowledge. There were too many different conditions, procedures and methods of informing them. Instead we asked the adults for their assessments. Parents were asked: `At what age do you think your child was or will be able to understand the details about the operation about as clearly as you do?' If the parent was a health professional we added: `Or about as clearly as an average adult?' (see table 3). We asked the health professionals, `What is the youngest age that you have found some of your patients can understand the relevant information in a fairly adult way?' We stressed that we wanted them to discuss actual cases, not children in general. We wanted to elicit an age when the professional would consider the perhaps rare possibility of mature understanding, rather than dismiss it as impossible. (see table 4).

Some adults would reply, `What do you mean by relevant?' and we asked them what the word meant to them. We were interested in the meanings behind the replies. The question was easier for parents because it was about their own child and the current treatment, and came at the end of an interview about relevant issues. For busy professionals, their often short interview opened with the questions which parents found most difficult.

Table 3 - Parents' views on when their child did/could have adult understanding of medical information.

Year group	Number of replies from 120 parents
under 6 years	8
6-10 years	49
11-15	45
16+	10
Don't know	8
Total	120
Mean	11.9 yrs

Mean scores exclude the 'don't knows'.

Table 4 - Professionals' views on when certain children could have adult understanding of medical information.

Year group	Number of replies from 70 health professionals
under 6 years	17
6-10 years	30
11-15	15
16+	1
Don't know	7
Total	70
Mean	7.3 years

The ages stated were complicated by:

- many adults not having thought about the issue before, and being surprised by the question;
- many adults preferring to give an approximate rather than a specific age;
- the view that understanding develops gradually so that it is hard to pinpoint a precise time of `adult' understanding;
- difficulty for parents in remembering how an older child might have understood a few years earlier, especially if they had not had surgery for some years previously;
- difficulty in imagining how soon a younger child might mature;
- uncertainty about how to define and assess understanding;
- beliefs about what children generally ought or could achieve, such as `not until they start GCSEs'.

Meanings of understanding

Two examples, of Brenda and Anita, illustrate the widely varying views of children's understanding, and how these depend on the adults' working definitions of `understanding' as well as the child's comprehension. Brenda's mother thought that Brenda could understand about her treatment `when she was six', at the time of her previous operation. Now aged nine, Brenda was having her third hip operation. `We took a lot of trouble to explain everything,' said her mother. During the interview the anaesthetist arrived, and before he spoke Brenda said, `Please can I have gas? I don't like the injection and please can I have the mint flavoured gas like I had last time?' The interview later continued:

<u>Int:</u> What is the matter with you?

<u>Brenda</u>: When I was a baby I had persecuted [dislocated] hips and so I had to have these operations to help me to walk properly. After the first and second operations they put a tube [plate?] in my leg and I think one in my hip as well, and then they put a large plaster on, and I had to lie flat for ages.

<u>Int:</u> What do you feel about having another operation?

<u>Brenda:</u> Well it will be worth it if I can do everything my friends do - run, jump, skip. I really like PE but I can't do it properly and they laugh at me and make fun of me. I get out of breath and it hurts and itches if I walk a long way. [Brenda was over-weight.]

<u>Int:</u> Do you think your operation was necessary, or very necessary?

Brenda: It is necessary. I didn't want to have the operation done, Mum persuaded me. I don't know how long I'll be in hospital. I'll be in plaster about six weeks because the older I am, the longer it takes to heal. Carolyn [nurse] told me I'll have a plaster on both sides to my ankle on the left and to my knee on the right.

While some people would say that Brenda's grasp of the technical terms and details was too hazy, others would say that she had a reasonable understanding of the purpose, nature and hoped-for benefits of the treatment.

Anita's mother was a radiographer and Anita, aged 15, planned to be a doctor. She had syringomyelia and had undergone neurosurgery the year before. Her mother said:

Syringomyelia is caused by Arnold Chirari malformation [ACM]. The cerebella protrude through the foramum magnum, where the spine is attached to the cranium. ACM causes the flow of cerebrospinal fluid to be interrupted, which causes a cavity in the spinal cord, a syrinx, which causes muscular wastage, sensory loss and maybe scoliosis - it affects people differently. Normally, it presents at 30 to 40 years. It is rare to have it so young as Anita.

Anita also had scoliosis which recently had become much worse, and her surgeon advised that she needed surgery urgently. Anita was upset about having another major operation, but was in continuous pain. She hoped that surgery might relieve the pain, but knew that the doctors were uncertain whether it would. Anita might be thought to be highly informed because of her experience, intelligence and interest in medicine. Her mother was, however, sceptical about informed consent.

I think 16 is as good an age as any to sign the form. But all consent forms are ludicrous - they have no legal basis, doctors can always claim that everything was explained. Even adult patients or parents are in no fit state to ask important questions - if they know what these are. And they can't remember the explanations later.

At each clinic they saw different doctors, who gave conflicting information until Anita's mother, because of her position in the hospital, was able to arrange that they always saw the consultant. The information greatly improved. When asked, `When do you think Anita was or will be able to understand the relevant medical information?' her mother replied, `It's very difficult to think back', and then decided `15', but added,

When Anita was nine, scoliosis was diagnosed. Shortly afterwards, when we were talking in an informal family gathering Anita said, `I want to be an orthopaedic doctor, because I will know what it feels like to be told you have scoliosis.' We were shocked, as she hadn't seemed at all bothered about the diagnosis, but she obviously felt very strongly about it.

Anita thought that she was as fully informed as her parents were, and the consultant had told her `a lot'. `I like to see the X-ray, You can actually see what is happening to you, not a general explanation. He always told me exactly what he was going to do and why.'

Anita's mother raised the problem of defining `understanding'. She seemed to be highly informed herself, but denied that parents could be. She may have classed herself as a professional who could understand, or felt that she did not meet her own exacting standards of an `informed' person. In contrast, some people accepted a grasp of basic principles as adequate. Among this group, a psychologist mentioned an `exceptional, brilliant' 3-year old with haemophilia.

Psychologist: He explained the nature of his illness and how he could do his injections himself, and what they meant and why he was doing it. He trotted it all out.

Int: Might he just have been fluently repeating adult phrases?

Psych: Oh no. I asked him questions to check that. It's not enough to be given information. I asked, `What do you do that for? What would happen if you didn't do it?' So I knew he had grasped the implications. If he'd said, `Because the doctors told me to,' or `I'd be naughty if I didn't do that,' that wouldn't count. But he really understood. He told me, `Because if I cut myself my blood is going to keep coming out and I'll get ill.' I asked him what `ill' meant and he told me.

One SHO described a 4-year old who was

very interested to see how his fracture was mending in each of his X-rays. Many children of three and four know the parts of their body and how they relate to each other, about their muscles and bones, and about things breaking and needing repairing. When my son was seven he had re-implantation of his ureters. I went to great lengths to draw and explain what was wrong and what the surgeon was going to do. I know he understood exactly what was going to happen so he wasn't frightened. I'm sure other 7-year olds are quite capable of understanding all the relevant information, as long as it is explained properly.

`Understanding' is not simply handling facts. It includes emotional awareness, coming to terms with shock and fear until hope and trust enable the person to take on the risk of having surgery.(Alderson 1990) Although Anita's mother defined understanding in intellectual terms, she recognised that Anita also `knows what it feels like', through personal experience. Patients have unique, direct knowledge of their own case, which complements general professional knowledge. A sister in a heart-lung transplant unit described this crucial aspect of understanding.

Sister: Children who have a chronic illness have an above average awareness of illness and what it means. A little girl of five who was dying of cystic fibrosis (CF), certainly knew 100 per cent that she had a lung disease, exactly why she was in hospital, that her lungs could no longer function, that in order to be well she needed lungs to come from somewhere else, that they came from somebody else who had died, who was on a machine and no longer needed them, and if she didn't get them she would die. She knew that death meant total separation from her parents. She knew that no one could tell her where she went to, but she never came back. Her hopes were that her parents would someday join her. So for a 5-year old she had total understanding of all that, and certainly they can take in a lot of information about the surgery...

Children who have an acute illness [often do not understand much because] their parents can protect them. But with children who have a debilitating illness, parents have to deal with them on a day-to-day basis of why they have to undergo various treatments. They have an understanding greater than mine.

Int: Are you saying that suffering and all the treatment, which might look from the child's view like abuse, increase their understanding? That is the opposite to the usual ideas about cognitive and emotional delay in chronically ill children.

Sr: It does vary, but we have seen almost 100 CF children who come for transplants, and the ones who don't know much stick out. Because if they don't understand about their illness, and its terminal nature, then they won't look on the transplant in any way as a positive experience. Only about ten children or less have been so protected from knowing how seriously ill they are. It's their

> armour. It isn't right for us in four days to take away that protection from them. Parents usually agree to go home and prepare their child. It's part of the role of the parent to protect children, but it depends how you decide to protect them. Thirty to 40 per cent know about the genetic component, and that it's inherited from their parents. They know they carry the gene, that boys are likely to be sterile, they know all these problems.

Developing inner awareness is an invisible, very personal process. It is usually ignored in studies of consent which attend to intellect rather than emotion, to overt measurable data, and to professionals' academic knowledge rather than patients' experiential knowledge.

Children's competence as wisdom

There are basically three ways of testing competence. Status: does the patient belong to a group usually assumed to be incompetent, such as being unconscious, senile or a young child? Outcome:is the decision competent in that it is likely to result in a desirable outcome? Function: can the patient pass tests of ability, either to decide about the particular operation, or to show general competence? (Department of Health 1989) Competence includes understanding what a prudent patient would want to know (in North America, Canterbury v Spence [1972] 464 F. 2d 772) or (in the UK, Bolam v Friern HMC [1957] 1 WLR 582) the more restricted standard of what a reasonable doctor would want to tell. Tests tend to set standards of abstract reasoning which many adults would fail. `Threshold' competence sets a definite boundary between `competents and incompetents'. `Degree' competence allows for an uncertain overlap between the two groups, realistically accepting that competence is usually assessed in doubtful, borderline cases.

The three methods sound formal and efficient, but we found muddle and overlap. People disagreed on what `desirable outcomes' might be in certain cases. Judgements of a child's ability were coloured by the assessor's beliefs about status. For example, a child psychiatrist who assessed children who refused surgery began by discussing function tests, but actually decided on status. He thought that discussing children's competence was `impossible', and `extraordinarily difficult outside a developmental context'. It could only be understood by expert doctors, trained to test children's reading and mathematical ability. (Hospital teachers thought a maths test was irrelevant. `It would only tell you whether the child understood that maths problem.') Most hospital staff, the psychiatrist felt, were `naive assessors', not trained to judge `intellectual development' or determine the `relevance' of information.

Psych: What children consent to may be a lot more or a lot less than they understand.

Int: Can it be called consent if they don't know what they're agreeing to?

Psych: That's the whole problem about consent. Of course they can consent, but if you're talking about a legal framework, what does consent mean? Does it carry the implication that if they don't consent they don't get it? Is consent purely a subjective experience, or does it in some way influence the other person?

The psychiatrist felt that young children could not grasp abstract concepts of preventative treatment and, `by and large, naive children don't have a concept of death till they're about ten. There are stages of death concepts - a book by a girl called Sylvia Anthony'. (Anthony's work published in 1940 and 1968 has long been challenged, such as by Bluebond Langner 1978.) The psychiatrist tended to see children as passive.

Informed consent means that you explain to them what is going on, and you say, `Do you understand?' And they can say `Yes' or `No', so they can give consent in that way. There is a difference between what a child says they understand and what an adult actually decides to do. I do think there are definitely occasions when children do not want a procedure to be undertaken. It should still be done... in the developmental interests of the child. I think children absolutely have that right to know exactly what is going to happen, why they are having it, the benefits of having it, and the risks of not having it.

Treatment is here implicitly benign, without risks or harms. The psychiatrist gave examples of children's `non-compliance' with dentists', teachers' and surgeons' decisions. He attributed these to `psychiatric disturbance, neurotic disorder, always in relation to family disturbance of some sort', and insisted that if refusal was `only due to fear' it must be overcome. Eventually when asked, whether he thought that operations could ever be unnecessary or unhelpful. He looked very surprised.

Psych: An operation unnecessary?

Int: Do you think children can't refuse? You seem to imply that children can't make rational choices. If a surgeon says, `You need this done,' and the child says `no', the surgeon is always right and the child is always wrong.

Psych: You mean the surgeon is wrong about recommending the need for surgery? [Long pause] Well. That's an interesting idea. Rather than that the child doesn't like the surgeon?

The psychiatrist appeared to be unaware of `grey areas' when, surgeons told us, they preferred children to decide. Asked whether he would actually enforce treatment, the summary of his long reply is: no, but,

We go on and on until we get what we think is right... It would be irresponsible not to make them have it... Otherwise one is colluding with the self-destructive behaviour on the part of the child.

Parents and children, who gave an age of competence of 16, 18 or 21, tended to believe `you're not allowed to before then' by law. They identified competence with `being grown-up'; `you can decide an operation when you're old enough to go out to work, or leave home'. Replies were affected by experience. For example, Kevin aged 11 may have been influenced by guilt and bad luck. His leg was injured in a traffic accident when he was seven. After three operations, including a skin graft when his leg became severely infected, he was critical of his local hospital which eventually referred him to a specialist centre. `They knew they done it all wrong, so they sent me here to the professionals.' His operation date was brought forward because his leg was so painful.

Int: Who do you think the doctors should talk to, your parents, or you or all of you?

Kevin: They should talk to my Mum, 'cos she understands more and she'll tell me.

Int: Who decided that your operation should be done now? Doctors, or parents, or you, or all of you together?

Kevin: Me.

Int: Who do you think should decide?

Kevin: Me, `cos the pain in my leg might be getting worse all the time, and if they leave it, it might get really bad. But, well, maybe it should be decided all together. I don't know. It's up to me, but if my mum and dad wanted it left until later, then

I'd have to go with them, 'cos they have to sign `cos I'm their son. And if I decide and then it goes wrong, then I'd get the blame.

Int: How old do you think you'd be when you were or will be old enough to decide?

Kevin: 18, 16. At seven, the parents can decide without the child, and after eight, they start talking with him.

Mother: I think Kevin is right. About eight you can start, and he could understand as well as I could at about eight or nine, and decide for himself when he's seventeen.

There was so much disagreement among our interviewees and in the literature about defining and assessing competence, as with understanding, that in our research we did not attempt to impose our own standards. Instead we asked interviewees how they defined and assessed children's competence. A more `scientific' method would be to break competence down into a set of questions, on children: being able to be consulted; wanting to be consulted; evaluating medical information; evaluating the personal context; wanting adults to decide; wanting to influence the decision; wanting to be responsible for the decision; making a range of small to major decisions; negotiating disagreement with adults; and so on. Yet separated replies may well have been stilted and hypothetical. Competence does not necessarily develop systematically, because major decisions do not arise in a child's life in any orderly sequence. Our open-response questions evoked much discussion which highly structured interviews would miss. Some people criticised the vagueness of our the questions. However, people from every age and background were bored and impatient if we tried seemingly repetitive, academic abstractions, whereas they were happy to tell detailed stories. An analogy would be to ask parents how their child learned to talk by questioning the development of pronunciation, syntax, vocabulary, and so on, instead of asking for the story of how a particular child started to talk.

When talking with children we merged understanding and wisdom into the single question: `How old do you think you were or will be when you're old enough to decide?' about the proposed surgery. Their parents were asked: `At what age do you think your child could make a wise choice?' about the proposed operation. When a mother and father were interviewed together, we took the younger age stated. The 70 health professionals were asked a different kind of question, to select from all their experience possibly exceptional cases: `Children vary greatly, but what is around the youngest age when you think some of your patients could be trusted to make sensible, wise, mature decisions about proposed surgery?' Children's and parents' replies are given in table 5, and professionals' replies in table 6.

Table 5 - Children's and parents' views on when the children could/might make an informed decision about surgery.

Number of replies from
120 parents120 children
Year group cited

under 6 years20
6-10 years812
11-15 5348

16+	37	36
Don't know	20	24
Total	120	120
Mean	13.9 yrs	14.0 years

Table 6 - Health professionals views on when certain children can make an informed decision about surgery.

Year group cited	Number of replies from 70 health professionals
under 6 years	7
6-10 years	24
11-15	25
16+	10
Don't know	5
Total	70
Mean	10.3 years

`Competence' has complex, partly contradictory meanings: the Kantian wisdom to make a correct decision and also the Millian courage to stand by a best guess, to take responsibility as a moral agent. Interviews were complicated by these conflicting meanings which could not be disentangled since each meaning is integral to modern meanings of competence. The tables only indicate approximate ages when children begin to be considered competent, as a general guide to the wide range of views on how certain young children are respected.

From hundreds of replies two extremes will be given here to indicate the very wide range of views. The highest age, in effect `never', was given initially by the surgeon, who said:

> Don't you think we're going in for over-kill with this consent business? Adults don't have the knowledge to make decisions. People should take their surgeon's instructions. I make it clear to them. `This is my opinion. If you don't like it then go elsewhere.'

Among the youngest ages cited for making serious and complex decisions was the heart-lung transplant unit sister quoted earlier. While discussing wisdom, she considered whether young children can have informed, constant values based in a firm sense of identity, the moral and rational basis of wise decisions. Her reply challenges the assertions of some texts quoted above, on children's cognitive and moral limitations.

Sister: A little girl of about seven with CF ended up by summing up what I had said beautifully. She said, `You're telling me that with CF you can get very ill and die'. I said, `We hope very much that won't happen, but that's why the doctors are thinking about whether, and it is only whether, a transplant might help you.' `And you said that I even if I say I want it, I might not live long enough to get one.' I said, `Well not everyone does. We think you probably will because you're fairly well at the moment but people do die waiting.' `And you're telling me that I could die when I have the operation.' `We haven't had anyone die in the operating theatre, but yes it could happen.' Then she said, `Even if I survive, you're not promising me that everything's going to be good, or that I will be able to do all the things I want to.' So I said, `When we put new lungs inside somebody, you should be able to do a lot more, but it's not a promise that anyone's going to be able to give you.' She said, `But, there is a chance that I could feel really good and I could come first in a race on my pony.' And I said, `Yes'. Then she continued, `All those other things are going to happen to me anyway, so please ask them to give me some new lungs.'

I think for someone of seven or eight to say that illustrates how she had totally taken on board as well as I could, the consequences of transplantation. She had managed to set it all out and look at it very clearly. She had understood the uncertainties. Okay, on a child's level, but who could better it? I couldn't.

I think it's very different when they have CF. Children who have been perfectly healthy don't have that perception of the value of life. Whereas these children were looking at certain death and exchanging that with the uncertainty of transplantation.

Int: So you think their suffering, rather than retarding their understanding, heightens it?

Sister: They are the most sure, mature children. They're physically immature, but their understanding of life and death knocks spots off us. I think they're immature in some of their attitudes, but their understanding of their own wellbeing and what life is all about is mature. Of course they have temper tantrums. They've got this debilitating illness. They've done nothing to justify being sick day in, day out. It's awful for them. But they tell you it all. Why they have this nebulizer, what this tablet does, et cetera. They're very manipulative children. Knowing that food is a major issue, they'll have steak at 2 o'clock in the morning. But that's very different to their actually understanding.

Int: It seems that suffering and difficulty help some children to grow. The usual convention is that this holds them back.

Sr: I think it often holds them back in some of the academic things because of missing school. They often have a poor concentration span, and their IQ may be lower.

Int: Some people have related IQ to wisdom.

Sr: I think it's totally, totally different. If I'd had this conversation with you three years ago, it would have been very different. Working with these children is a real eye opener. Perviously I'd have said that some level of understanding might be possible, say, for an 8-year old, but I would not have felt comfortable involving a child in actual decision-making unless they were at least 12-years or 13-years old.

Protective adults who want to spare children the risk of making harmful decisions with ensuing blame and guilt, themselves risk making harmful decisions and being resentfully blamed by the child. Yet sincere attempts to listen can sometimes resolve deadlock. A girl aged 10-years whose brother had died of CF refused to consider having a transplant. The sister respected her refusal, but added,

> The next day she asked to go on the waiting list, because, `You listened. I don't like physio but I'm told, "sorry you have to have it". It's the same with medication. I just wanted to see what would happen if I said "no". If you would take any notice.'

The girl's change of decision meant that treatment could be given with her fairly willing cooperation, instead of being withheld or enforced.

The ability to make decisions differs from the desire to do so. Among the experienced young patients, a few wanted the adults to decide for them. (This could be taken as a moral decision.) However, those who did not want to share in major decisions wanted to make `minor' choices, such as whether their parents could be with them. Most of the experienced young interviewees wanted some share, small or large, in making major decisions, such as Julie aged 11, who said, `I think everyone should give an opinion, and maybe the doctor put them together.' Thirteen children thought that they had been `the main decider' when we interviewed them again after their operation; their parents agreed. Kazim aged 15 who felt hopeless and excluded said, 'It's not the doctors' fault if something goes wrong. Your parent are to blame, because they've signed the form, it would be their fault.' However, other Muslim children in the study were much respected by their parents.

Competence tends to be formally assessed by examining qualities in the child - ability, maturity, and so on. Our interviews suggest two main conclusions. Factors around the child are at least as important - the attitudes and expectations of the adults, the degree to which children and parents are used to sharing decisions or keeping secrets, the quality of the information and support given to each child.(Alderson 1992) Also, to appreciate the wisdom of many people it is necessary to move beyond narrow concepts of intellectual problem -solving borne in lonely isolation, and to appreciate the contribution which interdependent relationships, and physical and emotional experiences make towards human competence. Instead of excluding people as irrational because of their anxiety and illness, we need to see how adversity can enlarge understanding.

Advantages and problems when respecting children's competence

The autonomy of adult patients is justified as a prima facie good in itself, and also as a source of further good, in that patients who are informed about and committed to their treatment are more likely to benefit from it.(Beauchamp and Childress 1983) Laws which assume that treatment can be enforced, if necessary, on uncomprehending and unconsenting children raise several problems. They sanction, in highly influential ways, the belief that adult might is right, though this has been identified as a major incitement to endemic child abuse.(Violence against children study group 1990) These laws ignore the growing evidence of very young children's ability to reason, to understand and misunderstand, to fantasise and to suffer mentally. Denying children's right to physical and mental integrity, through dismissing their rational competence, means that what would be assault to an adult is legitimate discipline to a child. Children are the only group left in UK society who are not protected by law from assault, either as enforced medical interventions or as physical punishment.(Newell

1989)

If young children experience unexplained treatment as assault, this opens a credibility gap between the child's perception of harm, and the adults' intention to benefit. Severe or prolonged treatment can induce terror and despair in the child. Children who perceive treatment as worse than the disease risk having similar reactions to those of torture victims. Torture is defined as `breaking down a person's sense of identity'. It is exacerbated when people are in a strange culture (such as a hospital ward). It arouses feelings of utter helplessness, being out of control of events and one's own body (inability to sleep, or concentrate, irritability), confusion between feeling bad and being bad, the disintegration of mind and body.(Melzac 1992) Stress and depression have been found in children as young as 2-years.(Yule 1992) If such feelings become habitual, children can be emotionally crippled. The higher the risks of treatment, the higher the chance that the child has severe, long-term sickness or disability which has already affected their confidence and self-esteem.

It can be argued that treatment decisions are either reasoned with patients or forced on them, and that reason and force are at opposite ends of a spectrum, with persuasion in the centre. Impartial, rational discussion is inevitably qualified by medical uncertainty, choice of words, pressures of the illness or disability being treated, and attempts to respect but also protect anxious children from frightening news. So persuasion overlaps broadly with reason at one end and force at the other. Yet at some point persuasion moves from informed optimism to deliberate distortion. Adults who gave high ages for consent tended to dismiss coercion as necessary firmness: `Kids only play up'; `They're only frightened', as if fear is irrational and therefore unimportant; `They've got to learn to put up with it for their own good'; `There isn't time to hang about until they're ready'. The most powerful way to justify coercion is to deny that children can be competent, and to align adult reason with force; children's resistance is then seen as mindless `self-destruction', to be overridden by rational adults.

Adults who respected competence at younger ages worried about the reason-force divide. A sister said, `I would always try to get a compromise.' A surgeon said, `I don't try and persuade people. If someone isn't happy with the idea of surgery, we'll talk again in a few months time, or a few years, and very often they've changed their mind.' Another surgeon commented,

> I regard the issue of consent as a partnership between parents, the patient and the doctor - none of these can work independently. The success of this depends on a lot of things, including the age and understanding of the child. Because of the risk that children will refuse necessary treatment, it is so important that the atmosphere is right, so that the child can voice their fears.

Forcing information onto patients who would rather not know can be a form of coercion, but was usually seen as the lesser evil to forcing treatment onto unprepared, resisting children.

Some interviewees believed that it is unwise and unkind to expect children to share in making major decisions; they were concerned about the neglect or abuse (through under- or over-treatment) which young people are exposed to if they take responsibility for their life. Others thought that children should be involved and that, given information, support, and time, they will usually arrive at an enlightened decision. These adults are concerned about the neglect or abuse which young people are exposed to if they are prevented from taking some responsibility for their life, and have to continue in enforced vulnerability and dependence. (Kitzinger 1990)

No one has the unqualified right to decide. The adults have responsibilities but not rights; the child does not have unrestricted choice, but has to choose `wisely'. In our study, children and parents usually agreed. In cases of disagreement a middle way could often be found of reasoning and compromise, until informed and willing consent was agreed. Such an approach depends on everyone taking the child's competence seriously. Our study investigated an unusual group of experienced children and we are cautious about over-generalizing. However, the understanding and maturity of this small group, mainly during adversity, raise many questions about the potential and actual capacity of all children, and the need for much more empirical research. This paper has dealt briefly with a few of the complexities of the vast topic of children's competence, and raises more questions than it answers.

Earlier, a comparison was drawn between women's and children's rights. In the past, in effect women had no rights; they depended on men's whim and on precarious privileges. The turning point for women's rights to resources, such as equal pay, and rights to protection, such as from rape within marriage, began with recognition that their reasoned assessments of their own interests could be valid: that women can be as rational as men. The turning point for rights to protection and resources for many children is linked to recognition that some children can be as rational as some adults, that young and old share a partial rationality. Only then will children's own assessment of their interests be taken seriously. Adults are not perfectly wise, but fallible, so that their rights to control children are questionable. Children do not have to be perfect to qualify as competent, that is, reasonably informed and wise.

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References

Alderson P (1990) Choosing for children: parents' consent to surgery Oxford/New York, Oxford University Press

Alderson P (1992) In the stars or in the genes? Children's competence to consent. Journal of Medical Ethics. 18:119-24

Alderson P (1993) Children's consent to surgery Buckingham/Philadelphia, Open University Press

Apter, T. (1990). Altered Loves: Mothers and Daughters During Adolescence. Hemel Hempstead, Harvester, Wheatsheaf

Aries, P. (1962). Centuries of Childhood. Harmondsworth, Penguin

Baker Miller J (1976) Towards a new psychology of women Harmondsworth, Penguin

Beauchamp T, Childress J. 1983 Principles of Biomedical Ethics. New York, Oxford University Press

Benton, T. (1977). Philosophical Foundations of the Three Sociologies. London, Routledge.

Bluebond Langner M (1978) The private worlds of dying children. New Jersey, Princeton University Press

Bradley, B. (1989). Visions of infancy: a critical introduction to child psychology. Cambridge, Polity Press

British Paediatric Association. 1992 Guidelines on the ethical conduct of medical research with children. London, BPA

Buchanan, A., Brock, D. (1989). Deciding for Others: the Ethics of Surrogate Decision Making. New York, Cambridge University Press

(Children's Legal Centre, 1991) At what age can I ...? Childright. 73, 11-14

Department of Health 1989). Code of Practice Pursuant to Section 118(4) of the Mental Health Act 1983. London, HMSO

Donaldson, M. (1978). Children's Minds. Edinburgh, Fontana

Dunn, J., Kendrick, C. (1982). Siblings: Love, Envy and Understanding. Cambridge Mass, Harvard University Press

Erikson, E. (1971). Identity, Youth and Crisis. London, Faber

Franklin R (ed) (1986) The rights of children Oxford, Blackwell

Gaylin, W., Macklin, R. (1982) Who Speaks for the Child? New York, Plenum Press

Gilligan, C. (1982) In a Different Voice. Cambridge Mass, Harvard University Press

Goodey C 1991 Fools and heretics: parents' views of professionals. In Booth et al (eds.) Learning for all. London, Routledge

Grisso, T., Vierling, L. (1978). Minors' Consent to Treatment: a Developmental Perspective. Professional Psychology. 9,412-27

Hendrick, H. (1990) Constructions and reconstructions of British childhood: an interpretive survey 1800 to the present. In James, A., Prout, A. (eds) Constructing and Reconstructing Childhood. Basingstoke: Falmer Press

Kant I (1948) Groundwork of the Metaphysic of Morals London, Hutchinson

Kennedy I 1988 Treat Me Right. Oxford/New York, Clarendon Press

Kitzinger J (1990) Who are you kidding? In Prout A and James A (eds) Constructing and Reconstructing Childhood. Basingstoke: Falmer Press

Kohlberg, L. (1981) The Philosophy of Moral Development. New York, Harper and Row

Kopelman, L., Moskop, J. (eds). (1989). Children and Health Care: Moral and Social Issues. Dordecht, Kluwer

Locke J 1924 Two treatises of civil government. London, Dent

MacIntyre A (1981) After virtue. London, Duckworth

Melton, G., Koocher, G., Saks, M. (eds) (1983) Children's Competence to Consent. New York, Plenum Press

Melzak S (1992) Secrecy, privacy, survival, repressive regimes, and growing up. Bulletin of the Anna Freud Centre, 15:205-224

Merchant, C. (1982). The Death of Nature. London, Wildwood House

Mill J S (1859/1982) On liberty. Harmondsworth, Penguin

Newell P (1989) Children are people too: the case against physical punishment. London, Bedford Square Press

Nicholson, R. (1986). Medical Research with Children: Ethics, Law and Practice. Oxford, Oxford University Press

Perrin, E., Gerrity, S. (1981). There's a Demon in Your Belly: Children's Understanding of Illness. Paediatrics, 67, 6, 841-9

Piaget, J. (1924) The Language and Thought of the Child. London, Routledge

Piaget, J. (1932). The Moral Judgement of the Child. London, Routledge

Piaget J (1957) Logic and psychology. New York: Basic Books

Robinson, R. (1991). Consent and confidentiality for adolescents in the US. British Medical Journal. 303, 539

Schnell, R. (1979). Childhood as ideology: a reinterpretation of the common school. British Journal of Educational Studies. 27, 7-28

Siegal, M. (1991). Knowing Children: Experiments in Conversation and Cognition. Hove, Lawrence Erlbaum Associates

Solberg A. Negotiating Childhood. In: James A, Prout A, eds. Constructing and Reconstructing Childhood. Basingstoke: Falmer Press, 1990

Violence against children study group (1990) Taking child abuse seriously. London, Unwin Hyman

Young A 1990 Moral conflicts in a psychiatric hospital. In Weisz G (ed.) Social science perspectives on medical ethics. Dordrecht, Kluwer

Yule W (1992) Post traumatic stress disorders in children. Current Opinion in Paediatrics, 4, 4

i. 'Children' is used as short hand for 'children and adolescents under 16'.