

## CONSENT: THE TREATMENT PARALLEL

It is sometimes helpful to approach a seemingly intractable dilemma from another one in which the issues are somewhat similar. The question of young people's consent to sex, for example, bears some resemblances to that of their consent to medical treatments. Both sets of dilemmas have to do with intimate and possibly invasive bodily procedures, in both there is an age difference and a presumed power difference, and in both cases the procedure has the potential to change the child's life permanently for better or worse. So these are not trivial matters; indeed, in the medical field at any rate, they can amount literally to issues of life or death. In both areas, too, the question of consent is a pivotal one - and not just in determining whether or not the procedure goes ahead; the *quality* of the consent - for example, whether it is given willingly or reluctantly - can radically affect the overall outcome.<sup>1-3</sup>

It is a contention of the present book that, outside of the barely relevant debate about chronological age, the question of young people's competence to consent to sex has rarely been seriously addressed. But even in the medical field, the notion that children aged under 16 should have any opinion about their treatment - let alone that the child's opinion should prevail - is a relatively novel one.

As medical students in the 1960's we were taught that consent was not an issue for patients aged under 16; the parents gave all the permissions and signed all the forms. Indeed, the idea that even the parents should have a say in treatment was not altogether welcome to some paediatricians of the day. Where consent to treatment of children was addressed in the literature, it was usually implicit that the "consent" was that of a parent or adult guardian.<sup>4,6</sup>

In 1986, however, the UK House of Lords decided in the Gillick case that children under the age of 16 could give valid consent to treatment if they had "sufficient maturity to understand what is involved" This landmark case, something of a *cause célèbre* at the time, related primarily to the right

### *Blood transfusion*

Some religious groups, notably Jehovah's Witnesses, refuse blood transfusions for scriptural reasons.<sup>9</sup> In the case of a young child where transfusion is considered medically necessary and parents refuse, Social Services may decide to seek legal guardianship, allowing transfusion to proceed without parental consent. Alternatively, and now more usually, they can seek a "special issues order" under the Children Act 1989; this would allow transfusion to proceed without parental consent but would not, as formerly, necessitate removal of the child from parental care.<sup>10</sup> Where an older child declines transfusion, it may be necessary for a judge to decide whether he or she is "Gillick competent" and, if not, whether the transfusion should proceed without the child's consent.

These matters can, understandably, be most distressing for all parties, but it may occasionally be possible to transfuse without offending religious sensibilities. For example, Jehovah's Witnesses sometimes accept "autologous" transfusion - that is, transfusion with their own blood that has been previously stored. However, this may also be refused. But in one instance, a boy of 12, a Jehovah's Witness, was successfully transfused (during a cancer operation) by an "autotransfusion circuit" method: his own blood was recirculated and expanded with dextrose and saline.<sup>11</sup> The details are unimportant here, but the case illustrates how consent is rarely an all-or-nothing matter, and that compromises can often be found that will satisfy all parties. It should be noted, however, that *refusal* of treatment - mainly because of its potentially dire consequences - is generally held to call for a higher order of mental competence than is *consent* to treatment.<sup>2,12</sup>

### *Research*

Traditionally, the "paediatric" dose of any medication is quoted as half the adult dose for children under 12, though for younger children body weight is also taken into account. But these relatively crude devices contrast painfully with the meticulous research undertaken by pharmaceutical companies to arrive at the correct adult dose, and there are a number of reasons, detailed by Kauffman<sup>13</sup>, why the appropriate dose for children cannot be calculated by such simple rules of thumb. In effect, the only

way to be certain that any medication is both effective and non-toxic in children is actually to test it on child subjects. Is it ethical to test drugs on children? Some authorities believe that, if doctors are to use any drug to treat child patients, it is unethical *not* to test it in children.<sup>13-15</sup>

In the past this was unquestioned, and clinical trials in children were conducted without consent and with little public scrutiny. Edward Jenner first tested his smallpox vaccine on his son and on neighbours' children, and Queen Caroline of England arranged for Jenner's vaccine to be tested on children from a foundling hospital before it was administered to the royal children. Even in 1958, 51 mentally retarded children in Willowbrook State School, USA, were fed with infectious material in order to study viral hepatitis.<sup>13</sup> This latter study when publicised, provoked an outcry and, among other developments, led to the establishment, in 1974, of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. It is now generally accepted that "competent" children should have the right to consent to, or refuse consent to, medical research.

But at what age are children competent to give such consent? Ondrusek *et al*<sup>16</sup> examined understanding of consent issues and clinical trials procedures in young children, and found that in children under nine years, understanding was "poor to non-existent"; the group concluded that, in children younger than nine, valid consent could not normally be obtained. Susman *et al*<sup>17</sup> examined 44 young people aged from seven to 20 years, testing their understanding of a range of research issues by means of a structured questionnaire. The children were under treatment for either cancer or obesity. The group found that understanding was very good in what they termed "concrete" issues - that is, all the children were clearly aware of the potential benefits and risks of the research, of their right to ask questions, of their role in the research, and their right to withdraw from it. But, not too surprisingly, there was less understanding of the more "abstract" issues surrounding the research - for example protocols and randomisation.

Interestingly, understanding of the main issues was not related to the chronological age of the children. But Susman *et al* observed that there was poor recall of many of the issues as the trial progressed, and recommended that the information/consent procedure should be continuous

throughout the period of the trial. The general conclusion, however, is that children aged nine and over are capable of giving valid consent to research and that such consent should be required.

The consent requirement and other recommended safeguards for children participating in research arise generally from three basic principles, defined in the USA by the Committee On Drugs of the American Academy of Pediatrics:<sup>13</sup>

1. Respect for the rights of the individual.
2. The obligation to protect the individual from undue risk
3. Fairness in distribution of the burdens and benefits of research.

Risk, therefore, should be minimal: studies in children should only be commenced after animal and adult studies have documented acceptable safety. There should be a clear expectation of benefit from the treatment. No particular economic or ethnic group should be selected unless the disorder under study is specific to the group (sickle cell anaemia, for example). Apart from reasonable compensation and reimbursement of expenses, there should be no financial inducement that would amount to coercion, particularly no inducement to responsible adults. Institutionalised or handicapped children should not be included in clinical trials unless the treatment deals specifically with their condition.

Finally, however, advocacy for children must include the *right to benefit from research* as well as the right to give or withhold consent.<sup>14</sup> But sometimes the word "assent" is used instead of "consent" in relation to children's participation in research - meaning that the child, while not legally capable of giving fully informed consent, understands the purpose, risks and benefits of the study, and agrees to take part in it.<sup>15</sup>

Great progress towards childhood autonomy has therefore been made in recent decades, but there is still some way to go. Even adults are only now being termed "participants" in research rather than "subjects".<sup>19</sup>

### *The 'right to die'*

In England in 1996, a young leukaemia sufferer was the subject of extensive media coverage because her local health authority had refused further treatment on grounds of cost. In spite of fierce public debate and a legal battle, the 10-year-old girl, who became known as "Child B", remained in complete ignorance of the issue. In a subsequent television programme Child B, who came across as intelligent and articulate, said that she had in fact seen the coverage, but been unaware that it related to herself. (She received treatment as a result of public donations, and survived for a further year.)

Examining the case in retrospect, Sellman<sup>20</sup> writes that the child's views might usefully have been sought before the clinical decision not to offer further treatment had been made and that, even without this, it was difficult to justify withholding the decision from her. Watching Child B tell her story, Sellman continues, served as a reminder that moral decisions are about the lives of people. He believes that those who failed to involve her in clinical decisions or to inform her about her prognosis may have been failing in an "ethic of care".

Child B badly wanted to live - as she made clear in her television interview - yet there were those capable of complicating even this simple matter. Unsurprisingly, the ethical questions become infinitely more tangled if a child *refuses* life-saving treatment. In what circumstances might a child have such a right? Can a child ever have the 'right to die'?

Some writers, in addressing the topic of life-threatening illness, completely sidestep the issue of child consent, for example Campbell: "I would argue that decisions involving the withholding or withdrawing of life-supporting care must continue to be made responsibly and compassionately in the child's interests by the doctor and parents". Campbell writes about the distress that might be felt by

parents in "allowing their child to die" but, in the course of a long paper, there is no acknowledgement that the child might also have a point of view on the matter.

Matters have, however, moved on since Campbell's 1983 view, and there is now a consensus that children with terminal illness should have the right, at the very least, to be informed about their prognosis and about any treatment decision.<sup>21-3</sup> The welfare check-list incorporated into the Children Act 1989 has as its first item "the ascertainable wishes and feelings of the child considered in the light of his age and understanding." But whether the child should have any final veto where life-saving treatment is concerned is more contentious, and a legal judgement is sometimes necessary. Since the introduction of the Children Act a number of cases have come to court on the issue of a child refusing to consent to medical treatment or investigation. One 12-year-old girl who was chairbound and had a suspected brain tumour refused a brain scan, but was ruled by the judge not to be Gillick competent and the scan went ahead.<sup>10</sup> In two other cases described by Stokes and Drake-Lee,<sup>21</sup> the children withdrew consent to surgery and, as they were judged competent, surgery was cancelled in preference to the use of force to induce anaesthesia.

This latter decisions were made by the medical team in consultation with the children's' parents. But where a case comes to court, there appears to be a tendency to judge a child who refuses treatment as incompetent mainly by reason of the refusal, while a child who agrees to treatment is, by contrast, more likely to be considered competent.<sup>10,12</sup> Children's rights advocates are critical of this seeming "Catch-22",<sup>12,24</sup> but most doctors would feel that the balance is about right, in that the scales should be heavily weighted towards the preservation of life. In particular, medical staff have a duty to protect a child - indeed anyone - against an impulsive decision made when he or she is too ill, or too depressed by the illness, to view the options rationally.

In practice, therefore, a child's absolute "right to die" would rarely be recognised, though Doyal and Henning<sup>21</sup> believe that adolescents who are deemed competent have the moral right to choose to die rather than to continue treatment. But they also believe that effective counselling and peer group support is essential, also a process of "partnership" with the medical team.

As a minimum, most clinicians would now accept that severely ill children should be informed of the options, should have a right to express a view, and that their view should be taken into account in the planning of further management.

### *Hunger strike*

In 1994 in Hong Kong, 1500 "boat people" - refugees from Vietnam - took part in a hunger strike in protest against the government's policy of forced repatriation. Sixty-seven hunger strikers were treated in hospital, including 57 children aged under 15; most of the children in the group were aged 8-12.<sup>25</sup> Some of the younger children had been coerced into the hunger strike by parents or community leaders, but some older children said that they had begun the strike voluntarily as they believed such action would reduce the risk of their being sent back to Vietnam.

The medical team was faced with a serious dilemma: according to the 1991 Declaration of Malta,<sup>26</sup> a doctor is required to respect the "sanctity of life", but also "the autonomy of the hunger striker". Yet at what age was a child to be considered "mentally competent to form an unimpaired and rational judgement concerning the consequences of such voluntary refusal of nourishment"? The team, in the absence of guidelines or previous experience, decided that allowing the children to fast would be "a form of child abuse" and children were not discharged from hospital until the team were satisfied that they would be fed normally. In the event, before serious problems developed, the hunger strike stopped.

A number of medical and legal authorities subsequently debated the issue in the columns of the *British Medical Journal*.<sup>27-30</sup> No-one doubted that coercion of a child into a hunger strike could be considered abuse, even "criminal neglect". The issue was less clear in the case of older children who were Gillick competent and who embarked on the strike voluntarily. Murphy<sup>29</sup> pointed out, however, that the Children Act 1989 only allows competent children to *have a say* in their treatment, and there was a general consensus that, while their autonomy of the children was important, the sanctity of life was even more so. Following from that, where the life of a child hunger striker was at risk, compulsory measures such as force-feeding would be justified. Therefore, by contrast with the cases

of some children who are severely ill, as above, medical opinion would not confer the "right to die" on child hunger strikers who had been initially healthy.

#### *Medical examination*

The Children Act 1989, while partly influenced by the Gillick decision,<sup>8</sup> also represented a response to the Cleveland child abuse inquiry and the report on it by Lord Butler-Sloss. (In the North of England, two paediatricians had examined children wholesale without consent, and had wrongly diagnosed numerous cases of "abuse"; large numbers of children had been taken into care and their parents arrested).

The relevant provision of the Act is s.38 (6):

"Where the court makes an interim order or interim supervision order, it may give such directions, if any, as it considers appropriate with regard to medical or psychiatric examination or other assessment of the child but, if the child is of sufficient understanding to make an informed decision, he may refuse to submit to the examination or other assessment."

It has subsequently been held that the High Court may use its inherent jurisdiction to overrule s.38(6) and may, in certain rare cases when all other remedies have been exhausted, order that a child be examined in the interests of its own welfare.<sup>30</sup> Otherwise, the situation cannot again arise where a UK paediatrician - or anyone else - may legally examine children without their consent or, in the case of very young children, without the consent of their parents.

#### *Organ donation*

Children of sufficient understanding have the right to sign donor forms giving permission for organs to be used after their death. A study among Spanish secondary school children, however, found that they displayed little understanding of the issues.<sup>31</sup> Most of the children were familiar with the concept of organ donation, but 34% thought that donors were paid and only 3% knew which organs were

transplanted most frequently. The authors write that organs for donation are scarce, and that awareness of the topic is important as ignorance is the main reason why consent is not given. They call for an information campaign to increase awareness and clarify misconceptions.

### *Beyond understanding*

Finally - in spite of the inherent emphasis of most research into childhood consent, it would be a great mistake to believe that consent has got to do simply with factual comprehension. A number of researchers have found that emotional factors weigh just as heavily as age or cognitive development in consent decisions, sometimes even more heavily.<sup>3,32-3</sup> These factors may be the wish to please a trusted adult, or the degree of confidence the child places in the medical staff. Pearce writes, in fact, that the *context* in which consent to treatment is given - that is, the quality of the relationships between child and adults - is of "critical importance". If there is a positive and trusting relationship with the responsible adults, the child will normally go along with what they advise; if not, "some children will deliberately do the opposite". And key relationships are not always with doctors and parents alone. A boy with muscular dystrophy was greatly comforted and supported by his older brothers, also sufferers, and a girl with cystic fibrosis agreed to undergo a heart-lung transplant so that she could ride her pony.<sup>1</sup>

### *Conclusions*

The area of consent to medical treatment remains an untidy one, and there are few widely agreed models of good practice. But great advances have been made in recent years, and it is now possible to extract from them a number of key principles. Whether some of these could also apply to sexual consent might be worth consideration.

- The child must always be respected as an individual, with his or her own rights, needs and wishes.

- Children may not be treated or examined without their consent or, in the case of incompetent children, without that of the responsible adult.
- Children aged under eight are normally incompetent to give informed consent. Competence emerges from the age of eight onwards, and children aged 12 or over should be presumed competent unless proven otherwise. All children, at the very least, should have the right to express an opinion, and their opinion should count.
- Consent does not have to do simply with factual understanding, but with the quality of relationships between the child and key adults. "Competent children usually know the adults who nurture their abilities, treating them as mature people", says one sociologist. "Competence is not just an individual skill, but a way of relating to others."<sup>1</sup>

## NOTES AND REFERENCES

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7. Mrs Victoria Gillick was, and still is, a vigorous campaigner on moral issues, opposing in particular the right of girls under 16 to receive contraceptive advice without parental knowledge and consent. It is ironic that her name is now attached to a key liberalising judgement.
8. *Gillick v West Norfolk and Wisbech Health Authority* [1986] AC 112.  
NB. All legal judgements quoted here apply only in England and Wales, though it is suggested that the general principles surrounding child consent apply universally.
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