Withholding consent to lifesaving treatment: three cases

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The refusal of children or their parents to consent to treatment that professionals regard as essential always results in a dilemma. Responding to such refusals demands careful and sensitive clinical and ethicolegal intervention and close cooperation among professionals, in particular doctors and social workers. Since the introduction of the Children Act 1989 the number of cases in which children have withheld consent to lifesaving treatment has risen, and it is now increasingly recognised that children have a right to have their views legally represented if a local authority or health authority seeks a court's leave to carry out treatment. Professionals have to consider which legal route, under either the Children Act or the Mental Health Act, is likely to be best for the individual child.

Since the introduction in October 1991 of the Children Act 1989¹ several cases have been brought on the issue of a child or young person refusing to consent to medical treatment or assessment.²⁻⁴ This is perhaps not surprising as the Children Act highlights the need for a young person or child to give such consent if he or she is deemed to be "Gillick competent"—that is, of sufficient understanding to make an informed decision.⁵

The ethical and legal issue of whether children can withhold consent to treatment has been discussed previously,^{6,7} and court decisions have been reported in legal columns. We report the cases of three patients at this hospital during 1993 in which consent was withheld and subsequent application to the courts was made. We discuss various legal issues and consider the complex professional teamwork necessary to try to ensure the best interests of the child patient and the merits and disadvantages of the different means of gaining consent.

The cases

CASE OF A

Although the refusal of Jehovah's Witnesses to agree to the use of blood products in treatment is not a new issue, it is interesting to note the legal process that we used in the case of A. A was a 10 month old baby at the time of referral. She had suddenly developed acute lymphoblastic leukaemia, for which she was immediately admitted. Because of her serious state she needed a transfusion of blood products within the first two days. A's parents, however, were Jehovah's Witnesses and could not consent to the transfusion because of their religious beliefs. A's condition was so serious that the doctors gave her the necessary treatment, without parental consent, using their responsibility and right as doctors to give lifesaving treatment in a crisis without the consent of the patient (or her parents). A's parents were willing for doctors to continue in this way, but the medical team was not prepared to do so because that would have meant that A would have to become ill to a life threatening degree

each time before blood products could be given, and that would have greatly jeopardised the chance of the overall programme of treatment being successful. It was clear that no other concerns existed about the quality of care given by A's parents; they were devoted to A and inevitably extremely distressed by the dilemma they were in, but they were firm in their religious belief. Their lack of consent, however, would certainly have put A at risk of appreciable harm.

Legally, application for a care order (or interim care order) may be made if a child is thought to be at risk of appreciable harm (usually because of the care given), and indeed a care order may be made only if this ground is proved. Because no other concerns existed about the parenting care of A, we decided after consulting the social work department to apply for a specific issues order under section 8 of the Children Act. A specific issues order may be applied for when a specific question has arisen about the welfare of the child; it is not necessary to prove that appreciable harm would occur without such an order. While in this case it would clearly have been possible to prove that appreciable harm would have occurred without such an order, the only issue to be resolved was how to gain consent to treatment. Applying for a care order seemed inappropriate since it would have implied a failure of parenting. In addition, a care order would have resulted in the local authority sharing parental responsibility with the parents for the duration of the order. This seemed to us an unjustified and inappropriate intrusion into the family's life.

The applicant for the specific issues order was the local authority—that is, the social services department of the hospital's local authority. The social services department of the child's home authority was kept fully informed throughout the legal process. Since the matter was complex the case was heard in the High Court, with the parents being represented. The case was heard in May 1993.

Court hearing

Discussions in court concentrated not so much on whether the treatment should be given as on the most appropriate legal mechanism for ensuring that the treatment could be given. Before the Children Act, wardship proceedings were often used to ensure that children whose parents would not consent to treatment because of their beliefs could none the less receive lifesaving treatment.

In the case of A the case for using the inherent jurisdiction of the court was advanced. Under section 100(4) of the Children Act the High Court may use its inherent jurisdiction to protect any child from appreciable harm by ordering a course of action which could not be achieved by a different legal order. In March 1993 Mr Justice Johnson had used the inherent jurisdiction of the court to order a blood transfusion in a child.⁸ In the case of A, however, Mrs Justice Booth judged that the application for and use of a specific issue order under section 8 of the act was the most

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appropriate way to achieve the desired end. The order made it clear that A could receive any blood products necessary for her treatment and in whichever hospital she was attending at the time (an important provision since children with leukaemia often receive shared care from two or more hospitals). The parents did not have any other restriction placed on them and in all other aspects continued to have sole parental responsibility; had A been made a ward of court, as would have happened before the Children Act, this would not necessarily have been the case.

CASE OF B

B was a 12 year old girl who had severe problems in walking and was wheelchair bound. She was admitted to the psychiatric unit of our hospital during an illness which had already lasted more than a year; she had previously spent several months in a psychiatric unit near her home. During her illness she had had many medical investigations for an organic cause of her symptoms. The shared professional view was that she had a conversion disorder. Although no history of specific trauma was discovered, complicated relationships existed in her family. B's natural parents, stepfather, and maternal grandmother all participated in her care and in her treatment. Although B showed anxiety and distress at times, she did not present as clinically depressed.

As is common in such cases, B was strongly resistant to the view that the cause of her illness was psychological, and her parents also had difficulty in accepting this diagnosis initially. The team treating B believed that it was important to have a neurological opinion to help the family not to fear the diagnosis and to reassure both the family and itself that no underlying organic disease existed. On examination the neurologist agreed that no evidence of an organic disease existed. However, the family asked for a second neurological opinion. When the second neurologist tried to examine B she was non-compliant, and he was unable to give a definitive opinion without her having magnetic resonance imaging. Her parents and the team agreed that this should be done, but B refused consent. She consistently expressed several fears about the imaging procedure and anxieties about its outcome and sequelae, regardless of whether it found an organic cause. Efforts (of family members as well as professionals) over time to help her to accept the investigation proved unsuccessful. On three occasions appointments were booked for the imaging scan, with attempts to meet all B's conditions, but on each occasion B refused the investigation.

This presented a dilemma to the team. The investigation was not medically urgent, and, indeed, the team members held conflicting views about the need for B to have it. The doctors believed that the investigation was most unlikely to show an underlying organic disease; but confirmation of the absence of such disease might help B and her family to accept with more commitment that the cause was psychological. On the other hand, if the scan did show an organic disease, the disease would be of a serious nature.

After much deliberation—including meetings with the neurologists and the community agencies from B's home authority and consultation with the legal departments of the hospital, the home local authority, and the local authority in which the hospital is situated—the team decided that the imaging investigation could not be done without an application to the courts. The team had been advised that as the merits of B having the investigation were not clearly medically overwhelming it would not be appropriate to force B to undergo it against her will without recourse to the courts. That advice was based both on the concern about the psychological effects on a young person forced to

undergo such an investigation against her will and on concern about hospital staff being accused of committing an assault by forcing her to have the investigation. The team's general view was that B was Gillick competent and that her judgment was not impaired cognitively or by any serious psychiatric disturbance; rather, her judgment was affected by her anxieties about the imaging investigation and its possible results. None the less, the team was uncertain how the courts would define Gillick competence.

Court hearing

The hospital made an application to the High Court. Initially the intention had been to apply for a specific issue order under section 8 of the Children Act. The team had been advised by lawyers at the time (February 1993), however, that it would be more appropriate to ask for B to be made a ward of court, particularly as the team definitely wanted the official solicitor to represent her interests—that would not necessarily happen in an application for an order under section 8. B's parents agreed to this course. At the initial hearing in April 1993 Mr Justice Ewbank gave leave for an independent psychiatrist to give an opinion. The psychiatrist believed that B was not Gillick competent.

At the final hearing in May 1993 Sir Stephen Brown judged that B was not Gillick competent and on that basis held that it was appropriate to give leave to the imaging investigation over and beyond the consent already given by B's parents. He confirmed the wardship, with care and control to the parents, and gave leave for the imaging investigation to be done. He said that if it was appropriate B should be told that the matter had been considered with great care.

B was told of the judgment and that it had been considered with great care; indeed, she had known about the process throughout, by meeting regularly with the hospital social worker and nursing staff, who kept her informed of each development. After the judgment, an appointment for the imaging investigation was booked, and B underwent the scanning without undue resistance or distress.

CASE OF C

C was a 16 year old young woman with chronic pain, especially in her abdominal area. Like B, she had had symptoms for over a year, with the onset following an appendicectomy. In 1991 depression had been diagnosed and she was admitted to her local adolescent unit for two months, but she had made no apparent improvement. In the summer of 1992 she was admitted to our psychiatric unit. Although she had a serious eating disorder, anorexia nervosa was not diagnosed; she was, however, assessed as clinically depressed, and she received psychotropic drugs and psychotherapy. No organic cause had been found for her chronic pain. Although neither she nor her parents had given any history of specific trauma, indicators in C's presentation led the team to decide that she had probably experienced some kind of trauma, although probably not in her immediate family.

She was treated with various drugs and psychotherapy and took part in several therapeutic groups and activities on the ward. During the first few months she showed some improvement, but during a prolonged Christmas break at home she deteriorated; on her return to the unit nasogastric feeding was started to increase her weight. Because of C's age and the length of her stay at the unit it was becoming clear that she would have to move to a longer stay unit for adolescents. C then refused to eat at all and said that she wished to die. The team thought that these actions were triggered by her proposed departure from the unit. Her refusal to eat and drink would probably lead to her being

Trying to ensure the best interests of the child

appreciably harmed and was indeed potentially life threatening. C's parents understandably were desperately anxious and wanted their daughter to be fed and treated.

The team had meetings with the social services department and local health professionals from C's home area. It was clear that C could be fed only by force, with a nasogastric tube. Nursing staff would have to hold her hands down as otherwise she would remove the tube; doing this without C's consent, however, could constitute an assault unless the issue was addressed in court. The team discussed which kind of court order to seek. Because of C's age and because she seemed to be Gillick competent it did not seem appropriate simply to override her refusal, despite the judgment of *Re W*.³ Some psychiatrists in other hospitals believed that an order should have been made under the Mental Health Act—in other words, C should have been sectioned. The hospital's social work department, however, believed that the Children Act should be used since this would probably lead to fewer long term disadvantageous sequelae for C than would an order under the Mental Health Act. Consequently, in April 1993 the hospital applied to the High Court under the inherent jurisdiction for consent to treat C against her will. Although the hospital made the application, in other similar situations it may be more appropriate for the local authority to do so as a minor would probably be appreciably harmed if an order was not made.

Court hearing

In April 1993 in an initial hearing Mr Justice Douglas Brown directed that C should be fed, forcibly if necessary. In a further hearing in May both the official solicitor and the hospital asked for C to be made a ward of court because it was clear that her welfare would probably continue to be of concern for a long time and that she would have to move to another hospital. Sir Stephen Brown agreed a wardship order and gave leave for continued treatment, feeding, and a range of medical investigations. She still requires constant psychiatric and medical care.

Discussion

IMPLICATIONS OF CASE OF A

Through her judgment in the case of A—namely, that a child's right to lifesaving treatment is paramount and must be considered before the religious beliefs of his or her parents—Mrs Justice Booth indicated the legal route that professionals should take in such cases.

She said that such cases should, whenever possible, be determined by a High Court judge. In view of the likely urgency, however, a district judge could always give necessary directions for a speedy hearing. The Children Act obviously allows a far better route for achieving this than did the previous legislation, which required either a care order or wardship, both of which could substantially affect the parents' responsibility and which could be perceived by the parents as questioning their parenting in a more general way—even when that was not the intention or view of the professionals or the courts. The judgment that a specific issues order is the most appropriate way to deal with situations in which the withholding of consent is the sole point of disagreement between a family and professionals is satisfactory to all concerned, including Jehovah's Witnesses.

Despite the judgment in A's case, we have reservations about using a specific issues order in cases in which we believe that the child should be independently represented. Making a specific issue order does not need the involvement of the official solicitor or independent representation of the child. In A's case we did not think these factors mattered. A was certainly not capable of instructing a solicitor. Recently a similar issue seemed likely to arise about the possible need for blood products after surgery in a 13 year old boy. The boy was a Jehovah's Witness and held strong views on transfusion. Had a legal process been necessary we would certainly have wanted the official solicitor to represent the boy and would also have considered his having legal representation independently of his parents, whether the application had been for a specific issue order or for the inherent jurisdiction of the High Court. In the event no application to the courts was necessary as the doctor treating the boy found a way of treating him that precluded the need for a transfusion of blood products.

Although it would certainly be possible in cases such as A's for the health authority to apply for an order, we believe that it is most appropriate for the local authority to do so since the child would probably be appreciably harmed if treatment was not given. Moreover, the local authority has the statutory responsibility for investigating and acting in cases in which a child may be suspected of being at risk of appreciable harm. In the case of A we decided that the hospital's local authority should start the proceedings because of the urgent need for action (delays were possible if professionals from the child's home authority had to be briefed).

IMPLICATIONS OF CASE OF B

In the initial hearing in April 1993 much of the discussion in court hinged on whether B was competent or not competent. The disagreement among the psychiatrists giving opinions about whether she was Gillick competent may reflect an uncertainty about how to define Gillick competence—it may indeed need to be interpreted legally rather than clinically. Both the hospital and the official solicitor hoped that the judge would give guidance on how to deal with future cases that were medically non-urgent and in which a minor was neither Gillick competent nor a ward of court. In particular, they hoped that they might be guided on how to avoid seeking the leave of the court to proceed with the treatment. However, Sir Stephen Brown did not do this; he said that in future cases application to the courts should be made so that each case could be decided on its merits. His decision on whether B was competent seemed to be based on the same grounds as Lord Donaldson had used in *Re W*³ and which *Devereux et al* have argued are illogical⁶—that is, disagreement denotes that the child is incompetent, and agreement denotes that he or she is not competent.

We do not know whether courts will continue to judge that minors who withhold consent to investigations or treatment that is agreed by their parents and advocated by professionals are not Gillick competent. If they do, the implication is that a minor can be Gillick competent only if he or she gives consent, not if he or she refuses it, even in non-urgent situations. This interpretation is in line with the judgments already made by Lord Donaldson in *Re R (a minor)*³ and in *Re W (a minor)*³ and in the judgment in *South Glamorgan (County Council v Ward B)*.⁴ In the case of *Re R* the minor was judged to be not Gillick competent because of her psychiatric illness and so could not give a valid refusal. In the case of *Re W* the girl had anorexia nervosa and was refusing treatment, and her condition was life threatening; Lord Donaldson judged that consent to treatment by anyone with the right to give it, either the minor or those with parental responsibility, outweighed refusal by any other person. In the *South Glamorgan* case a 15 year old girl who was living in an extremely reclusive manner but was assessed as not suffering from a psychiatric, psychotic, or personality disorder was made the subject of an interim care order, with directions under section 38(6) for her to receive inpatient psychiatric assessment and treatment. As she still refused consent her wishes were eventually overruled by powers under the inherent jurisdiction of the High Court.

Other judgments have overruled the views of adults who were refusing consent to treatment in situations in which a likely or certain risk to life existed if treatment was not given.⁹ In one case a pregnant woman refused consent to a caesarean section; the High Court authorised the section to be done. In another case a 20 year old woman refused a blood transfusion after a road traffic accident; the judge held that her refusal was not properly informed because of her fluctuating medical condition and that she was unduly influenced by her mother, who was a Jehovah's Witness. While the first case was brought to court under the Children Act, the second was not.

Application for order

Which agency should start the application for an order? We believe that in cases such as B's where the issues involve complex medical arguments and the minor is not likely to be appreciably harmed regardless of whether the treatment or investigation is carried out, it may be appropriate for the relevant health authority to make the application. Obviously this should always be done in consultation with the social work department of the hospital, and that of the home authority if the authorities are different. The primary arguments are medical not social, and are not based on child protection issues. Social workers have a role, however, in ensuring that the child has as broad an assessment as possible—that is, an assessment that takes into account his or her wishes and the possible pressures put on him or her by parents, other family members, or indeed professionals and which also assesses the family and its responses to both the child and the medical advisers.

In B's case, when the application was originally made to court there had not been any test cases with a specific issues order, although that had been the initial recommendation of the social work team. The ruling in the case of A (a month later), however, advocated the use of specific issue orders in similar situations, and we advise applying for a specific issues order when the issue of treatment or investigation is relatively clear cut and when the child does not have to have independent representation. A specific issues order may not be appropriate in cases such as C's in which wide ranging, long term issues and the possibility of changing treatments and placements will probably arise.

IMPLICATIONS OF CASE OF C

The judgment in the case of C followed the judgments made in the cases of *Re R*² and *Re W*³; treatment and feeding or hydrating, or both, should occur even if C opposed it. The courts, therefore, will apparently not permit a minor to bring about his or her own death by refusing treatment. At C's final hearing the hospital's request for C to be made a ward of court was also granted, with care and control given to her parents.

Using Mental Health Act or Children Act

Whether to use the Mental Health Act instead of the Children Act may be an issue in cases such as C's and indeed was raised by medical staff in her case. The Mental Health Act is used in some adolescent psychiatric settings in similar cases to C's. The act allows for much quicker resolution; the court process under the Children Act in C's case took almost six months, with two hearings for directions. Obtaining a section under the Mental Health Act takes only a few days and would still allow for an independent second opinion. The cost would be minimal compared with the cost of court proceedings, especially if the proceedings are in the High Court. As C was made a ward of court, even though care and control rested with her parents, her civil status might have been affected for the remainder of her minority.

Using the Mental Health Act may be seen as treating a young person as if he or she was adult and so acknowledging his or her age and maturity without dispute. It may be unhelpful, however, to put too great a burden of decision making on children and young people, and in situations of major difficulty and disagreement, an independent view perhaps should be sought in the courts.

The clearest disadvantage of the Mental Health Act is that being the subject of an order under that act carries risks of long term discrimination. Discrimination may occur when a person seeks a visa, insurance, or possibly even employment. Although none of these examples of discrimination will necessarily apply to any given individual, when they do apply to a person they may do so for life. Such a disadvantage does not occur with the Children Act.

The second important disadvantage of the Mental Health Act is that it does not allow the patient a fair voice in the proceedings. This has to be compared with the considerable time and care given to a minor in a situation such as C's when the Children Act has been used. Indeed in C's case, because of her age the professionals discussed whether she should be represented independently of the official solicitor. Although it is possible to appeal against an order under the Mental Health Act, an appeal can only be made after the proceedings. The young person does not therefore have a definite voice or representative during the proceedings.

Despite the disadvantage of the prolonged proceedings under the Children Act a long period for continued discussion (provided that an initial hearing for directions gives permission to treat or feed urgently) may have benefits: the minor can perhaps still be helped to agree to the treatment, and certainly he or she can be helped to understand fully the issues and process involved.

Finally, a traumatic cause all too often exists for serious presentations in children and young persons such as in C's case. These causes are likely to have implications for child protection.

We believe that in cases such as C's it is most appropriate to use the Children Act rather than the Mental Health Act. Indeed, although in the case of C the hospital applied for the order, it might in similar cases be more appropriate for the local authority to do

so, in close cooperation with the medical team, as the minor is at risk of appreciable harm if treatment or feeding, or both, are not enforced.

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- 1 *Children Act* 1989. London: HMSO, 1989.
- 2 Re R [1991] 3 WLR 592-608.
- 3 Re W [1992] 3 WLR 758-82.
- 4 South Glamorgan County Council v W and B [1993] 1 FLR 574-86.
- 5 Gillick v West Norfolk and Wisbech Area Health Authority [1986] 1 CA 112-207.
- 6 Devereux JA, Jones DPH, Dickenson DL. Can children withhold consent to treatment? *BMJ* 1993;306:1459-61.
- 7 Freeman M. Removing rights from adolescents. *Adoption and Fostering* 1992;17(1):14-9.
- 8 Re O. *Times* 1993 Mar 19.
- 9 Lewis C. Freedom of choice. *Law Society's Gazette* 1992;89(46):27-8.

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Recent Advances

Clinical pharmacology and therapeutics

Alasdair Breckenridge

Therapeutic practice rarely changes greatly as a result of a single investigation or trial. Traditionally, experiments carried out in the laboratory lead to small scale studies in humans, some of which may be translated into larger controlled clinical trials, which, if successful, may begin to influence patient management. The time scale of this process varies greatly. At one end of the spectrum a new biotechnology product may be developed with great rapidity, tested in a small cohort of patients, and be used by specialists within seven to eight years of its initial design. On the other hand valuable information on drugs of proved therapeutic value may languish in the literature for some 10 to 15 years before being widely accepted into clinical practice (for example, thrombolytic drugs after myocardial infarction). Dissemination of the results of research is as important as the original research itself, and implementation may represent an even bigger hurdle.

It is not an easy task to describe the advances in clinical pharmacology and therapeutics over the past year. I will start with the general issue of cost effective prescribing, which has moved up the political agenda in Britain after the publication of two influential reports. I will then cover four specialist therapeutic areas (AIDS, post myocardial infarction management, neurodegenerative disease, and diabetes), where treatment has become clearer because of positive or negative trial results. Finally, I will discuss the clinical exploitation of experimental findings on nitric oxide, which will have important roles in many diseases.

Cost effective prescribing

The issue of therapeutic cost effectiveness is not new, but several events have occurred recently to give the topic special prominence. Firstly, the latest reforms in the NHS have left all health care professionals questioning how burgeoning drug costs, which now account for £3.3bn out of a total NHS budget of £30bn, can be contained without prejudicing patients' welfare. Secondly, the Audit Commission, which is responsible for the external audit of the NHS in England and Wales, has turned its attention to prescribing in general practice¹ and identified several areas where savings could be made. The commission calculated that some £425m of the total general practice prescribing budget of £2.6bn in England and Wales was being wasted in overprescribing, in using drugs of limited clinical value, or in using expensive drugs where cheaper ones are equally effective (including generic equivalents). Though the commission recognised that many new expensive drugs had important

roles, it said that their introduction had to be managed carefully. Expensive prescribing is not always bad, but neither is it necessarily good. Expensive drugs used to prevent disease—inhaled steroids in asthma being a good example—might initially produce a rise in cost but could lead to reduction in hospital admission and thus overall savings (fig 1).

FIG 1—Patterns of prescribing for asthma in a sample of 3409 British practices. Source: Audit Commission

Thirdly, the health committee of the House of Commons issued its second report on priority setting in the NHS in 1994 and examined the NHS drug budget.² It made some interesting recommendations on both the pricing of drugs and their availability. The profits of the pharmaceutical industry from the NHS are currently negotiated in great secrecy between the Department of Health and the industry. The committee recommended that this process should be more open, saying that the impermeable secrecy which surrounds the working of the scheme militates against public confidence. The committee also recommended that a national prescribing list should be created so that at an appropriate time after licensing a drug would be reassessed for cost effectiveness and its suitability for funding by the NHS. In effect, this would extend the current selected list to all therapeutic areas. The government has now published its response, and though it has promised to consider many of the committee's recommendations, it has pleaded for time to implement them.³ The pharmaceutical industry's response is awaited with considerable interest. I believe that the topic of cost effective prescribing will remain the most important in therapeutics for several years to come.

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