

Priscilla Alderson (2000) The rise and fall of children's consent. *Paediatric Nursing* 12, 2: 6-8.

This article traces how the rise of respect for children's consent during the 1980s has fallen during the 1990s, and questions whether lawyers and doctors can be relied on to make fair decisions for each child they consider. Using examples mainly drawn from heart surgery, the article concludes that medical and legal decisions would be better informed if more account was taken of children's and parents' views.

The 1980s

In England and Wales, people aged over 16-years can give valid consent to treatment according to the Family Law Reform Act 1969 s.8. The consent of people under 16 is legally valid if their doctor considers that they are competent to make an informed and wise decision (Gillick 1985; Age of Legal Capacity (Scotland) Act, 1991 s2 (4)). The 1989 Children Act, and similar Acts for Scotland and Northern Ireland, state that children deemed to be competent can 'refuse medical or psychiatric examination'. The United Nations 1989 Convention on the Rights of the Child, ratified by the British government in 1991, emphasises the best interests and welfare of the child, which include adults listening respectfully to the child's views 'on all matters affecting the child' (UN 1989, article 12). More than a charter, a Convention is the strongest kind of international treaty. The 1989 Convention has been ratified by every government expect for two, unprecedented support, and ratification means promising to implement the Convention in law, policy and practice,. However, since 1991, English law has become more ambivalent about minors' consent.

The 1990s

Reports in 1998 and 1999 about enquiries into children's heart surgery at Bristol indicate that, when a child dies or is brain damaged, parents increasingly channel their protests through allegations of doctors' negligence to inform parents fully about the risks of surgery in order that parents may give informed consent or refusal. However, English legal cases during the 1990s show that, despite doctors' rising anxieties about litigation concerning consent, the courts have increased doctors' control over parents' and children's consent or refusal.

In 1991, Lord Donaldson in the Court of Appeal began the 'backlash against Gillick'. He ruled that R, aged almost 16 and refusing mental health treatment, could be forced to have medication (In re R [1991] 4 All ER 177). In 1992 he ruled that W, aged 16, who had anorexia could be force-fed against her wishes (In re W [1992] 4 All ER 627). This overturned the 1969 Act mentioned earlier which respected 16 year olds as having adults' rights of consent. The 1989 Children Act increased the potential number of people with 'parental responsibility', and Lord Donaldson further ruled that if any one of these adults gave consent, this could overrule the refusal of everyone else concerned including the 'Gillick competent child' aged up to 18. The details are discussed in Alderson and Montgomery (1996).

Both rulings were criticised by lawyers on several grounds, including the point that mental illness affected one if not both cases, which would have been better dealt with using the Mental Health Act 1983. Lawyers warned against generalising from these exceptional cases to all teenagers and children, but this has happened. Since 1992,

doctors often mention that 'the law does not allow children to refuse'. Of course children can refuse, no law can stop them. The legal and also ethical questions are whether doctors should override refusal, or should respect the informed decision of a child they deem to be competent.

It is likely that there are many unreported cases of doctors and parents gradually coming to accept the child's informed refusal, even with (almost certainly hopeless) attempts to prolong life with repeated surgery, chemotherapy or organ transplantation. Samantha's wish, when she was 6-years-old, to refuse a third liver transplant was reluctantly accepted by her parents and doctors, for example (Irwin 1996). Yet professional and public attention is drawn to the series of reported court cases which have all authorised doctors either to treat or not to treat as they originally intended, and have ruled against children's and parents' wishes. The sole exception, was a very young boy whose parents refused a liver transplant for him (re T 1997). These parents were intensive care nurses and it seems that, exceptionally, their views counterbalanced the expert medical views which the courts usually favour against the families' lay views. Court cases are based on precedent, and so each case confirms previous ones. Doctors have great power to shape legal judgements and individual patients' and parents' consent. When they wish to proceed with treatment they can emphasise the hoped-for benefits. When they consider it best to withhold or withdraw treatment, they can emphasise the pains, risks and uncertainties of treatment (Silverman 1981; Zussman 1992).

Medical authority was taken still further when doctors were authorised to transplant a new heart into M, aged almost 16, despite her refusal. Previously healthy, she had developed heart disease a few weeks earlier and a transplant was proposed a few days before the court hearing (Dyer 1999a). M was quoted as saying, 'Death is final - I know I can't change my mind. I don't want to die, but I would rather die than have the transplant and have someone else's heart.' The judge, Mr Justice Johnson said that he was 'very conscious of the great gravity' of overruling M's wishes: she might resent this for the rest of her life, and the already high risks of the surgery not being successful might be increased by M's unwillingness. Yet he concluded that M was 'overwhelmed by her circumstances and the decision she was being asked to make. Events have overtaken her so swiftly she has not been able to come to terms with her situation.' to make a competent decision. Yet M's reactions are typical of the initial stages of consent to heart surgery. Consent involves a process, not simply an event. People of any age begin with a dilemma between mutually incompatible ends, such as gaining health and avoiding surgery. Gradually they think and feel their way towards a resolution, such as preferring treatment to the untreated condition. They begin to let go of some desires and hold to others more strongly (Alderson 1990). At first, the dilemma is inevitably confusing, but the person is not necessarily confused.

The desperate urgency felt by M's parents and doctors and the judge is understandable. Yet it is unfortunate if such an exceptional case encourages the belief that, when an extreme procedure such a heart transplant can be enforced, almost any other procedure can also be enforced on minors' whose views need not count. Adults' own refusal has to be respected in English law, to the extent of respecting women's refusal of Caesarean section even if the baby might die (in re S 1998). This case reversed and criticised two earlier decisions in 1996, by M's judge Mr Justice Johnson, that Caesarean sections could be performed against the women's wishes. One of the women said that she would 'rather die' than have a second Caesarean and the Judge commented, 'I concluded that a patient who could speak in terms which seemed to

accept the inevitability of her own death was not a patient who was able to weigh up the considerations.' His view contrasts with those of the senior nurse in a children's heart-lung transplant unit who believes that it is only when children accept the high possibility that they might die that they are able to give informed consent (Alderson 1993, chapter 9).

Newspapers compared M's case with cases of force-feeding girls with anorexia (London Metro, Daily Mail, 17.7.99). They ignored the great differences between administering food and implanting a heart, and between patients with a physical condition and those with anorexia which is linked to mental disorder. Most seriously, emergency court rulings undermine the respect for informed and willing consent which, to many practitioners, is an integral part of therapy - even for young children as far as they can understand.

Despite the judge's report that he had considered M's views, her views were unlikely to influence the inevitable precedents-based legal outcome of supporting medical opinion. This inevitability was demonstrated in two further cases in July 1999. David Glass's mother failed to obtain a court ruling that treatment should not be withheld from her severely disabled son, aged 13 (Dyer 1999b). The courts also upheld consultants' refusal to refer Katie Atkinson aged 9, who has Down's syndrome, to be assessed for a possible heart transplantation as her parents had requested.

Katie's case illustrates controversies about children with Down's syndrome. They have a high incidence of heart defects but not one, so far in Britain, has had a heart transplant. Although the Department of Health declared in news bulletins on 26 July 1999 'there is certainly no ban on people with Down's syndrome receiving organ transplants', politicians leave doctors to select the patients who they think will have the best chances. So far, clinicians have excluded children with Down's syndrome because, for example, of their shorter life expectancy. Yet since less than half the transplanted cases survive for more than ten years (Heart 1999 82:47-51), the expected survival time is well within the lifetime of children and teenagers with Down's syndrome. Many kind of minor and major medical treatments are withheld from children with Down's syndrome (Julian-Reynier et al 1995) which partly accounts for their shorter average life span, so that to deny treatment to children because of shorter life expectancy can be a circular argument. Children with Down's syndrome may be considered less worthy of costly care because of their average lower intelligence. Intelligence tests of children with Down's syndrome found a range from 10 to 92 or almost the centre of the normal range (Lorenz 1984). As more children with Down's syndrome are educated in mainstream schools, their achievements, and expectations about them, are rising considerably, and in the future are likely to influence medical decisions about their treatment. A London theatre group of people with learning difficulties who create and act plays, including 'A change of heart' about a Californian woman with Down's syndrome denied a heart transplant, 'Breaking the mould' about genetics, and 'Mongol Boy' about exclusion, is one instance of their skill, creativity and contributions to society.

The transplantation unit sister mentioned earlier discussed children's desire to share in decisions about transplants.

All the children we see have demonstrated an ability to make their own decisions....I would say that often as young as four or five they can understand a lot about a transplant. Of course, it varies very much, and you can't generalise. I believe the child always has to be involved. We know that they

literally have their life in their hands afterwards. If they stop taking their medications, for example, they will die.

The paradox, of doctors taking one girl to court to enforce a heart transplant on to her, is that there are many people longing and dying for that heart. On 27 July 1999, a British television Horizon programme reported that about 250 heart transplants are done in England each year, about 50 at Papworth Hospital which started this surgery in 1979. One in ten people die while on the waiting list after a rigorous 3-day assessment, another one in ten die after surgery. Half the hearts sent for transplantation are too damaged to use, and they last for only four hours after being removed from the 'donor'. Recipients have a 50/50 chance of surviving for 10 years, and a 20-49% chance of dying within one year. You have to be very ill to be put on the waiting list. Thousands of people are waiting for a heart transplant.

Summary

It is often assumed that doctors and lawyers make fair case-by case medical-legal judgements based on each person's best interests, followed by effective treatment. Yet judges are tied by precedent and by the Bolam tradition of accepting agreed medical opinion. They do not force doctors or health authorities to provide any treatment, though they usually authorise doctors to treat if the doctors wish to. Child B who was denied end-stage experimental cancer treatment is one of many such examples. Lawyers and doctors are influenced by public opinion, such as wide spread prejudices about disabled and aged people, and who is 'worth' treating, or not. Even if they decide to proceed, nature may intervene with high attrition rates of people waiting for and receiving transplants. The high risks, and the current limits of medical skill and knowledge point to the importance of involving the most informed and willing recipients. It is crucial that doctors work closely with children and parents, informing them, such as about the limits of medical skill and learning from them. Paediatric nurses can play a key part in promoting this exchange.

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earlier notes to store

1999

In July 1999, the High Court authorised doctors to transplant a new heart into M, aged almost 16, despite her refusal. Previously healthy, she had developed heart disease a few weeks earlier and a transplant was proposed two days before the court hearing (Dyer 1999a). M was quoted as saying that she did not want to die but that she did not want a new heart either. She understood what the procedure involved and was concerned for her family's feelings but she did not want to 'have someone else's heart'. She added, 'If I had children and they were old enough, my age, I would go with whatever is best - what they want. I would not let them die' Although might sound a contradiction it could mean that she would not casually let - leave them to die, but neither would she force them to live, she would stand by their decision. M shows the illogic of laws which deem someone incompetent to decide one day, and competent the next day on their sixteenth or eighteenth birthday. Competence and respect for young people do not suddenly arrive on a magic day. However, the judge concluded that she was too over-whelmed to make a competent decision.

Yet M's reactions are typical of the initial stages of consent to major surgery; consent is a process, not simply an event. People of all ages begin with a dilemma of mutually incompatible ends, such as gaining health and avoiding surgery. Gradually they think and feel their way towards a resolution, such as preferring treatment to the untreated condition. They begin to let go of some desires and hold to others more strongly. At first, it is the dilemma that is inevitably confusing, but the person is not necessarily confused in the sense of incompetent.

The urgency felt by M's parents and doctors and the judge is understandable. Doctors said she had only a week to live and they would have to start immediately to search for a suitable heart. Yet why did they take the exceptional patient who refused to court, when they have waiting lists of people who are already longing and dying for a new heart? Many of them will never be able to have one.

It will be unfortunate if such an exceptional case encourages the belief that, if an extreme procedure such a heart transplant can be enforced, almost any other procedure can also be enforced on minors' whose views need not count. In contrast, adults' own refusal has to be respected in law even if, for example, a woman's refusal of a Caesarean section might end in her baby's death. The following day, newspapers compared M's case with ones of force-feeding girls with anorexia. They ignored the great difference between administering food and implanting a heart, and between patients with a physical condition and those with anorexia which is linked to mental disorder. 'I'm so glad a judge ordered me to live' was the London *Evening Standard's* front page headline (16.7.99), misleadingly suggesting that M was speaking. The speaker was actually a young woman with anorexia who was glad she had been forced to eat two years earlier. 'She'll be happy she [M] was given the chance....I understand completely how she feels,' the quotation continued, showing how little the commentator understood M's real position.

The paper's leader writer praised the judges 'wise judgement'. 'One day she may well come to thank him for it.' But what if she does not? Thirty years ago when heart transplants were first carried out, there was initial wide-spread revulsion which quite soon changed to admiring support for heroic doctors and patients as successes were highly publicised, and the failures were less well known about. Yet even when society generally accepts heart transplants, and some societies such as Japan do not yet do so, individuals faced with a personal experience have to think deeply about what it means to lose your own heart, to have another's beating inside you all your life, and to

regard other people potentially as sets of spare parts. Two days is a very short time to work through such momentous realisations. M was reported as changing her mind and giving her consent before the operation. In that case, was it necessary to go to court and not to wait a little while longer? Her psychological and physical recovery are likely to have gained from her being able to voluntary non-coerced consent. Staff in heart-lung transplant centres stress the importance of finding the most cooperative and willing patients, because of the scarcity of spare hearts, the risks and burdens of the treatment when less than half of the recipients survive for more than ten years and many organs are rejected, and because of the life-long daily follow up care. 'Their lives are literally in their hands' as one senior nurse in a children's unit said (Alderson 1993). Most seriously, emergency court rulings undermine the respect for informed and willing consent which, to many practitioners, is an integral part of therapy.

Despite the judge's report that he had considered M's views, her views were unlikely to affect the inevitable legal outcome of supporting medical opinion. This inevitability was demonstrated in two further cases in the same month. David Glass's mother failed to obtain a court ruling that treatment should not be withheld from her severely disabled son, aged 13 (Dyer C 1999b Mother fails to win right to control treatment for son. BMJ 319:278). The courts also upheld consultants' refusal to refer Katie Atkinson, who has Down's syndrome and is aged 9, to be assessed for a possible heart transplantation.

This case illustrates controversies about people with Down's syndrome. They have a very high incidence of heart defects but have not so far in Britain had a heart transplant. Although the Department of Health declared in news bulletins on 26 July 1999 'there is certainly no ban on people with Down's syndrome receiving organ transplants', politicians leave doctors to select the patients who they think will have the best chances. So far they have excluded children with Down's syndrome because, for example, of their shorter life expectancy. Yet since less than half the transplanted cases survive more than ten years (Heart 1999 82:47-51), the expected survival time would seem to be well within the lifetime of children and teenagers with Down's syndrome.

1989 was a highpoint for respect for children, the year of the Children Act and of the United Nations Convention on the Rights of the Child which both endorse listening to children. The Convention speaks of assuring '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 being given due weight in accordance with the age and maturity of the child' (article 12). In England, Wales and Scotland, the law went beyond the Convention in allowing that minors would not only contribute to decision making but could be the main decider, able to give legally valid consent if deemed by the doctor treating them to be legally competent.

Suddenly things changed in 1991 when Lord Donaldson in the Court of Appeal began the 'backlash against Gillick'. He ruled that R aged almost 16 could be forced to take psychiatrist medication which she was refusing. In 1992 just before he retired he ruled that W, aged 16, who had anorexia could be force-fed against her wishes, so overturning the 1969 Act mentioned earlier which respected 16 year olds as having adults' rights of consent.

Both rulings were criticised by lawyers on several grounds, including the point that mental illness affected one if not both cases, so that they would have been better dealt with using the Mental Health Act 1981. Lawyers warned against generalising from these exceptional cases to all teenagers, but this has happened. Health professionals frequently say 'by law children cannot refuse'. Of course, children can refuse, no law

can stop them from doing that. The question is whether doctors can legally override their refusal. Lord Donaldson said that they could and that as long as the child and or anyone with parental responsibility for the child consented, even if a 'Gillick competent' child refused, doctors could safely proceed with treatment. The consent of any one person was the key which unlocked the way to treatment.

Since 1992, a series of reported court cases has authorised doctors either to treat or not to treat as they originally intended, and has ruled against children's and parents' wishes. Court cases are based on precedent, and so each case has confirmed previous ones. The courts also take 'expert medical advice' which is favoured over the families' 'lay views' and the child's 'wishes and feelings' (as the Children Act describes them in somewhat emotional rather than rational terms).