Lessons for health care rationing from the case of child B

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More details have emerged about the child B leukaemia case with the publication of the All England Law Report on the Appeal Court decision. At the time the view was widely held that the controversy might have been avoided if the responsible health authority had consulted the public. The law report reveals, however, that the courts adopted a moral language widely at variance with that of the patient's doctor. The courts were concerned to support a utilitarian decision procedure based on calculations of the greatest overall good; the doctor was concerned with the best interests of a sick child. The doctor-patient relationship may be damaged when public consideration transforms the issue in this way. Also, the Appeal Court supported a decision which claimed to have "weighed" opposing evaluations, but it excused the health authority from describing how that weighing took place. One of the main criticisms of the utilitarian approach, however, is that weighing of this type is extremely difficult to justify. By its ruling the court has made legal challenge on the grounds of inadequate consultation virtually impossible to substantiate.

The case of child B came to prominence almost a year ago. Widely reported as an example of explicit rationing in the new NHS, it concerned a young leukaemia sufferer who had been refused a second transplant operation by Cambridge Health Authority. The child's father challenged this decision in the High Court, where the authority was told to reconsider its refusal. The case then went to the Appeal Court, where the decision, or at least the authority's right to make such a decision in the manner it did, was upheld. Despite this victory, what caught the headline writers' attention was the High Court's ruling that in such serious cases, "the responsible authority . . . must do more than toll the bell of tight resources."¹ It had to show, the judge said, the grounds on which its decision was made. The *BMJ*, among others, was quick to point out that public grounds would be available only after public consultation for, since everybody had an opinion about what was right, the only thing to do was find out where the balance of opinion lay—there were no experts in such questions.² Suddenly, the Oregon model of health care rationing (in which the list of treatments that would be publicly funded in Oregon was decided in consultation with the public) was back in the spotlight after the flurry of interest it had created in the early 1990s.

The resort to utilitarianism

A more complicated picture emerged when the All England Law Report on the Appeal Court ruling was published.¹ Two aspects of the case are striking. The first concerns the courts' determination to view the case in a utilitarian light—that is, in terms of the greatest good of the greatest number. The second

concerns the practicability of using the utilitarian approach in cases such as this.

Both courts used the familiar idiom of utilitarianism when considering the moral aspects of the decision. According to the Appeal Court, "Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients."¹ By contrast, the doctor responsible for the patient did not talk like this at all. She told the court that when her patient went into relapse and was given only a matter of weeks to live, she considered both the chance of success of further treatment and the suffering it would cause and decided that "it would not be right to subject [B] to all this trauma."

There is no mention here of the greatest good of the greatest number; the child's moral claims are not waived in the name of some greater good; the value of her life is not set against the cost of treatment and the number of other patients who might otherwise be treated. The doctor made a practical judgment in the case of a family she had known for more than five years. She contemplated the likelihood of death and practically assessed how dying might be made as peaceful and dignified as possible for the child and her family. What happened in the public domain that turned this moral approach, based on the impulse to help a suffering child, into a calculation which quite explicitly weighed the child's life against the alternative use of scarce resources?

The child's best interests was the underlying argument

The usual answer to this question is that rationing had been implicit all along. It was only because in this instance the treatment being considered had to be provided outside the health authority's usual contract that the issue had come to light, and perhaps it was a good thing that it had for now there could be open discussion on a point of justice. But in this case there is no evidence to show that the doctor was modifying her clinical judgment with considerations about resources. On the contrary, she said that she acted in the best interests of the child and the child's family, and only in those interests. The question of the greatest general good did not arise—and there was no need for it to arise so long as practical judgments were confined to the doctor-patient relationship and compassion for the child. In short, there are important areas of life where it is both unnecessary and inappropriate to make judgments in which the consequences for an individual are weighed against the consequences for society. Acting out of compassion required no other grounds and no other grounds would have supplied better reasons.

With the decision lifted out of the confines of the doctor-patient relationship the health authority and the court considered the views of the doctor insufficient. They invoked general welfare as the best

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The original grounds for offering no further treatment to B were very different from those that the courts ended up arguing about [since this article was written the courts allowed B's identity to be revealed to enable her family to raise money to support her further treatment]

ground on which to argue the decision, demonstrating a belief not only in the efficacy of the utilitarian enterprise but also in the responsible authority's right to interpret this enterprise in any way it chose. The court made the crucial ruling that an authority need not show how it derived and applied its calculations of welfare. This was not something, according to the master of the rolls, that an authority "can be fairly criticised for not advancing before the court."¹ But the High Court had said this was insufficient. It told the authority to show how the conflicting interests had been weighed, if they had been weighed at all.

Two sets of questions arise from the Appeal Court's judgment. Firstly, was this in fact a decision which had been referred to considerations going beyond the doctor-patient relationship. Secondly, if it was, what were these considerations, how did they arise, and how were conflicts among them resolved? The health authority and the Appeal Court had a role in clouding the answers to all of these questions.

Clouding the issues

Thus the health authority wrote to B's parents that its decisions would be taken with "B's best interests in mind" and not "on financial grounds." On that account its interventions would add nothing to the procedures of the doctor-patient relationship. However, the authority deposed to the Appeal Court that it had made the decision (to refuse treatment) because the treatment would not be "an effective use of resources," its funds were "not limitless," and it had to consider the interests "of other patients." So in court it was not a case of "B's best interests" but the interests of B somehow weighed against the interests of unnamed others; and financial grounds did number among the considerations. These contradictions lay behind the words favoured by the secretary of state when she described the decision as "a medical judgment on funding," a phrase which managed to suggest that a question of morality had been settled scientifically.³

As well as a contradiction in the health authority's formal account of its reasoning, there was also confusion over the substance of considerations. Decisions about what to do depended in the authority's analysis on getting opinions, weighting them, and deliberating in some way. But the High Court had drawn attention to the fact that the health authority, in

listing the opinions it had sought and saying what weight it had attached to them, nowhere mentioned the opinion of the child's father or what importance the authority attached to it.

This argument was rejected by the Appeal Court, which ruled that the whole process of deliberation implied that the authority was "vividly aware" of the parent's view. It saw no reason, therefore, to describe as unfair a system largely devoted to finding grounds for rebutting the parental case. And where the High Court had called for some account of the steps involved in calculations like this, the Appeal Court responded that this was an unreasonable expectation. In a society like ours, it said, "a high value was put on human life." If the health authority had ruled that £75 000 (the cost of the treatment) was not "an effective use of resources" then this was an intelligible though painful line to take. It was not for the court to say whether the judgment was valid; this depended on the way the authority had balanced opinion.¹ But this was a process the authority could keep to itself. An authority need only utter the mantra "having had regard to" when reporting its decisions, and a court could consider it to have deliberated legally.

In disagreeing with the High Court, the Appeal Court ruled that the authority was not under a legal obligation to show how this judgment had been reached. In other words, an authority remains within the law if it can show that it is broadly conscious of different points of view; it is not under an obligation to show how it decides among them.

Lessons

Several lessons emerge from all this. Firstly, the affair reached the courts only because a doctor and a patient's parents failed to agree over the right course of action to take in a particular case. Was this breakdown in the relationship of trust exacerbated by the health reforms of the internal market and the spread of private medicine? If so, then the doctor-patient relationship may be said to be under threat from these reforms.

Secondly, when the case became public the rational structure of the issue changed. It ceased to be about B's best interests and about responding to suffering and became instead an issue of costs, benefits, and resource availability. But when this happened, how did one persuade a parent what was and what was not worthwhile? What public reasons could support the claim that a 1 in 5, or even a 1 in 50, chance of success was too slight to be an effective use of resources? The problem had been stood on its head. It was because the doctor held child B in high regard that she acted as she did; when the health authority got involved it became a matter of justifying the same decision by showing how child B should be held in lower regard on a scale of values. Whatever the technical merit of the prognoses, one thing they did not do was settle this question of value. In Oregon public consultation was invoked at precisely this point. What, asked the Oregon Health Commission, would most people find most satisfactory? But putting the matter like this does not rebut child B's moral claim; it simply ignores it. And besides, how could public consultation have been geared to the case? Was it ever feasible to maintain, as it was maintained at the time, that the public could have expressed their preference for transplants for young children in relapse with acute lymphoblastic leukaemia?

Thirdly, the Appeal Court held that the essential mystery at the heart of utilitarianism, its procedures for balancing conflicting viewpoints, could be left untested. This is a peculiar position for utilitarianism to occupy. It is commended as a superior approach to moral questions in health care but excused from

demonstrating its superiority. At a time when health authorities around the country are "having regard to" the views of winners and losers as they rationalise acute services and close hospitals, it is a judgment which bodes ill for those who choose to go to law over the adequacy of public consultation. It is, if nothing else, a judgment well fitted to radical change.

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- 1 R v Cambridge HA, ex p B judgment [1995] 2 All ER 129.
- 2 Smith R. Rationing: the debate we have to have. *BMJ* 1995;310:686.
- 3 Hall C, Mackinnon I. Cancer girl loses fight for treatment *Independent* 1995; 11 March: 1, col 4.

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Minocycline induced autoimmune hepatitis and systemic lupus erythematosus-like syndrome

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Minocycline is the most widely prescribed systemic antibiotic for acne largely because it needs to be given only once or twice a day and seems not to induce resistance. Up to April 1994 11 cases of minocycline induced systemic lupus erythematosus and 16 cases of hepatitis had been reported to the Committee on Safety of Medicines. An analysis of these cases together with seven other cases shows the severity of some of these reactions. Two patients died while taking the drug for acne and a further patient needed a liver transplant. Acne itself can induce arthritis and is often seen in association with autoimmune liver disease, but the clinical and biochemical resolution seen after withdrawal of the drug, despite deterioration of the acne, suggests a drug reaction. In five cases re-exposure led to recurrence. Because reactions may be severe early recognition is important to aid recovery and also to avoid invasive investigations and treatments such as corticosteroids and immunosuppressants. Safer alternatives should be considered for treating acne.

Minocycline is a semisynthetic tetracycline antibiotic with a broad spectrum of activity, which first became widely available in 1972.¹ Because it is more lipid soluble than the older tetracyclines an oral dose is almost completely absorbed and it has excellent sebum penetration. Its long half life, allowing once or twice daily dosing, makes it popular with both patients and doctors. Indeed, minocycline is now the most widely prescribed systemic antibiotic for acne,² and the only one to which drug resistance has not yet been described.³ In 1993 there were 63 998 prescriptions for minocycline in the West Midlands region alone at a cost of £1.7m, reflecting the broad usage of this drug.

Until April 1994 there had been 11 reports to the Committee on Safety of Medicines suggesting drug induced systemic lupus erythematosus and 16 reports of hepatitis associated with the use of minocycline. In this paper we review these data and report on seven cases that show the clinical presentation and potential severity of these adverse reactions.

Subjects, methods, and results

The early inflammatory arthritis clinic at Selly Oak Hospital was set up in 1990 to identify, document, and follow up cases of inflammatory arthritis of recent onset. During the first three years two young women taking minocycline presented with a symmetrical polyarthrititis affecting the small joints of the hands and wrists, and another presented with polyarthralgia of the same distribution (see table 1, cases 1-3). The clinical appearance suggested early rheumatoid arthritis or systemic lupus erythematosus. All three

patients were strongly positive for antinuclear antibodies and had been taking minocycline for acne for two months to two years. One patient (case 3) had presented two years previously with a fever of unknown origin and similar polyarthralgia. She had started minocycline six weeks before this presentation and had subsequently discontinued it until two months before her second presentation. Withdrawal of the drug led to rapid resolution of symptoms on both occasions. This index case led to the suspicion that minocycline might be implicated, as all three patients had similar presentations and were positive for antinuclear antibody (but not for antibodies to DNA or to extractable nuclear antigens), and all symptoms resolved quickly on withdrawal of this drug.

At presentation another patient (case 1) was found to have hepatitis with a serum aspartate transaminase concentration of 385 IU/l. Viral hepatitis and liver autoantibody screens gave negative results. A liver biopsy confirmed chronic active hepatitis. The hepatitis resolved completely after minocycline was stopped. Furthermore, on review of the notes, the index patient was also noted to have had raised aspartate aminotransferase concentration of 98 IU/l at her first presentation. Again no cause was found, and these tests returned rapidly to normal after discontinuation of minocycline.

Having determined that minocycline could cause an autoimmune drug reaction leading to hepatitis, we looked for further cases prospectively in 1993 and found four more (table 1, cases 4-7). Three of these (cases 5, 6, and 7) were again young women taking minocycline who developed severe hepatitis and were positive for antinuclear antibody. The fourth (case 4) was a 37 year old man who had also been taking long term minocycline for acne. He initially became jaundiced in February 1993. He did not present to his doctor at this stage, but five months later, after the jaundice resolved, he became unwell again. He had severe hepatitis with an aspartate aminotransferase concentration of 2320 IU/l, with a strongly positive antinuclear antibody titre. Although he was still taking his minocycline at this stage, we do not know whether he took it continuously throughout. Cases 5 and 7 presented with jaundice and all three women experienced profound malaise and polyarthralgia in addition to their hepatitis. In all, liver biopsies showed moderately severe changes of acute or chronic active hepatitis. Apart from antinuclear antibody, hepatitis viral screens and other autoantibody tests gave negative results. All seven patients' symptoms and laboratory investigations returned to normal within three months of their discontinuing minocycline. Although their acne deteriorated, all seven have had no recurrence of symptoms or biochemical abnormalities to date, emphasising that these reactions were likely to be drug related.

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