

# Education and debate

## Tragic choices in health care: lessons from the Child B case

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Four years ago the case of Jaymee Bowen, more commonly known as Child B, captured the newspaper headlines. The coming together of a father who was determined to seek the treatment he believed was best for his daughter, doctors who disagreed about what treatment was appropriate, health service managers who were prepared to take a stand on the use of resources on services of questionable effectiveness, lawyers willing to test the decision of the health authority in the courts, and journalists who saw the case as exemplifying the dilemmas of health service decision making meant that Jaymee's story caught the public imagination and highlighted the challenge of rationing.<sup>1</sup> The way in which the case was handled contains important lessons for decision makers in health authorities and primary care groups charged with making difficult choices in health care.

### Jaymee's story

To understand the significance of the case it is important to recount some of the detail of what happened at the time. Jaymee Bowen was an articulate and lively 6 year old when, in 1990, she was diagnosed as having non-Hodgkin's lymphoma. She was treated at Addenbrooke's Hospital in Cambridge, but in 1993 was diagnosed as having a second cancer, acute myeloid leukaemia. Jaymee underwent chemotherapy and a bone marrow transplant for the treatment of her leukaemia at the Royal Marsden Hospital in London. Only nine months later—at the beginning of 1995—she relapsed, and the paediatricians responsible for her care advised that she had 6-8 weeks to live. Their view was that a child with Jaymee's medical history was unlikely to benefit from further intensive treatment, and they recommended palliative care.

Jaymee's father, David Bowen, was not willing to accept this advice. His response to the opinions expressed by the doctors at Addenbrooke's and the Royal Marsden was to do his own research in the hope of finding a cure. He did this by reading books and medical journals, by using his brother who lived in the United States to track down information and contacts, and by contacting doctors at home and in hospital. His search eventually led to California, where he found two doctors who were willing to recommend that Jaymee should receive a second bone marrow transplant.

David Bowen presented the results of his research to the paediatricians responsible for Jaymee's care. In the light of Jaymee's medical history and the paucity of research into the outcomes of second transplants, they

### Summary points

The Child B case showed that decisions on funding experimental and costly treatments raise ethical and practical dilemmas

Concern to use resources for the benefit of the whole population has to be weighed against the urge to respond to the needs of individuals

The decision making process must be rigorous and fair

Decision makers should explain the reasons behind decisions, show that these are relevant, give the opportunity for appeal, and ensure the process is regulated

Not all these conditions were fulfilled in the Child B case—health authorities and primary care groups should learn from this experience

were surprised that the specialists who had been contacted in California had recommended further intensive treatment. Whereas their own view was that Jaymee's chances of going into remission after chemotherapy were around 10%, with a similar probability that a second transplant would be successful, the advice from the United States was much more optimistic. The paediatricians reiterated their opinion that palliative care was the best way of improving Jaymee's quality of life.

At this point David Bowen arranged to see an adult leukaemia specialist at the Hammersmith Hospital. The view of this specialist was much more positive than that of the paediatricians. He put Jaymee's chances of going into remission after chemotherapy at 20%, at which point a second transplant could be considered. Heartened by this opinion, David Bowen approached the Cambridge and Huntingdon Health Authority to ask if it would pay for treatment at the Hammersmith Hospital. The authority declined. Its director of public health argued that the paediatricians who had been responsible for Jaymee's care were in the best position to assess treatment options, and that the authority was not prepared to use resources on experimental procedures with a limited chance of success.

David Bowen had reached the end of the options available to him and contacted his solicitors to seek



Jaymee Bowen's story raises a series of ethical and practical issues in regard to use of resources in the NHS

leave for judicial review to challenge the authority's decision. This was granted. The High Court took the view that the health authority should reconsider its decision, arguing that the right to life was so precious that the authority should think again, even though the chances of success were acknowledged to be low. This judgment was overturned on appeal. The judges in the Court of Appeal, reaffirming the reluctance of the English courts to challenge health authority decisions on the funding of treatment, ruled that the authority had weighed the advice it had been given and that therefore there was no basis for the decision to be reviewed.

In response to media coverage of the court case, an anonymous donor offered to provide funds for the treatment. David Bowen accepted this offer through his solicitors, and treatment started in the private sector. In the event, the specialist who took over Jaymee's care decided not to undertake a second transplant, but instead used an experimental form of treatment known as donor lymphocyte infusion. This treatment enabled Jaymee to enjoy a few extra months of life. David Bowen believed that this vindicated the actions he had taken, even though Jaymee became ill again and eventually died in May 1996.

### Ethics of priority setting

Jaymee's story raises a series of ethical and practical issues of continuing relevance in the NHS. Most importantly, it demonstrates the tension between a concern to use resources for the benefit of the population as a whole and the urge to respond to the needs of individuals faced with the prospect of death. Although

not motivated primarily by the costs of chemotherapy and a second transplant (estimated at £75 000), the Cambridge and Huntingdon Health Authority did take into account the likely benefit to be achieved from a sizeable financial outlay and the opportunity costs involved. In Jaymee's case, the combination of the high cost of treatment and the low chances of a successful outcome, against a background of clinical opinion that advised against further intensive treatment, were decisive considerations.

The balance of costs and benefits looked quite different from David Bowen's perspective in that the alternative to going ahead with a transplant was the prospect that Jaymee would die within a matter of weeks. Even though he recognised that he was "taking a calculated gamble," as the father of a dying child he felt that this was a chance worth taking in what were desperate circumstances. Although David Bowen did not use this language, he was unconsciously invoking the "rule of rescue" in seeking help for Jaymee.<sup>2</sup> This "rule" suggests that when individuals are suffering life threatening conditions there is an obligation to intervene even when this may run counter to the concerns of the community as a whole.

The ethical dilemmas faced by health authorities have been reviewed by Draper and Tunna, who note the challenge of meeting the needs of all individuals with the resources available. Although health authorities have a particular responsibility to ensure justice in the allocation of these resources, they are also expected to respect each individual as a person in his or her own right. In a case such as that of Child B, Draper and Tunna comment: "In adjudicating a special claim on resources, by an identifiable individual, who is likely to die quite quickly if resources are not forthcoming, commissioners may feel compelled to assist, even if they would not consider the small possibility to benefit worth the cost under other circumstances, perhaps where death is not imminent."<sup>3</sup>

In Jaymee Bowen's case the arguments were more complex because the view of the child cancer specialists was that the potential harm involved in the act of rescue was likely to exceed the potential benefit. Their experience of witnessing the adverse effects of intensive treatment on children like Jaymee urged caution in offering anything other than palliative care. Put another way, they felt that there was no obligation to observe the rule of rescue when rescue becomes futile and pointless because no reasonably effective treatment exists.

In these circumstances, the Cambridge and Huntingdon Health Authority had to grapple with the dilemma that adult cancer specialists viewed the balance between harm and benefit differently from the paediatricians. In taking on this role, the authority was guided by a set of values it had adopted to inform its work as the commissioner of health services. These values enabled the managers involved to test the options in relation to the impact on equity, appropriateness, effectiveness, efficiency, responsiveness, and accessibility. Like the child cancer specialists involved in the case, the authority felt that the evidence on appropriateness and effectiveness was of particular importance in the decision not to proceed with a second transplant.

The question that arises from an ethical perspective is whether the rule of rescue would have prevailed over utilitarian considerations if an effective treatment had been available. The health authority pointed out that at the same time as refusing to fund a second bone marrow transplant for Jaymee Bowen it had agreed to pay for treatment for a patient with haemophilia at a cost of over £200 000, because in this instance the advice received was that this was an effective and appropriate use of resources. Much more problematic for the advocates of the rule of rescue is the increasing number of cases in which marginal benefit is available to patients at high cost. It is in these cases that the ethical dilemmas of priority setting are particularly acute and when the basis of decisions—the issue we now turn to—becomes important.

### Process of decision making

The wider importance of the Child B case lies in the lessons it holds for those responsible for making tragic choices in health care. Among these lessons, the implications for health authorities and other bodies in the position of weighing the needs of individuals and the interests of the community are particularly important.

The Cambridge and Huntingdon Health Authority was ultimately successful in defending the legal challenge to its decision and felt that the ruling in the Court of Appeal vindicated the approach it had taken. This approach centred not only on the use of a set of values to inform decisions of this kind but also on a thorough process within the authority for assessing the evidence and considering alternatives. In this process, the director of public health took the lead and discussed the case with the authority's chief executive and chairman. The head of administration was also involved, and these individuals reviewed the medical advice and evidence available before deciding not to acquiesce to David Bowen's wishes. When the case came to court, the authority was able to show that it had considered the evidence carefully and that the decision was not simply the result of one individual's judgment. It was also able to show that it had kept careful records of the case and the advice sought from clinicians. For these reasons, the way in which the case was handled was seen as exemplary by the Department of Health.

Yet in making this point, it is important not to underestimate the scope for improving the process of decision making in cases of this kind. Given that there will often be controversy over tragic choices in health care, it is incumbent on those responsible for decision making to show that they have followed due processes and have been both rigorous and fair in arriving at their decisions. This is especially so in cases where an individual's life is at stake and when standard treatments have been exhausted. In this context, the research carried out by Daniels and Sabin into decisions on the funding and provision of new technologies in managed care organisations in the United States offers an interesting parallel to experience in the United Kingdom.<sup>4</sup> As Daniels and Sabin argue, in circumstances in which patients and their relatives may fear that treatment is being denied on the basis of cost, decision makers have to be able to

show that this is not the case if they are to invest the decision making process with legitimacy.

### Accountability for reasonableness

Put another way, decision makers have to ensure "accountability for reasonableness" in decisions on health care coverage.<sup>5</sup> Specifically, Daniels and Sabin propose four conditions that need to be met to ensure accountability for reasonableness:

(1) Publicity condition: decisions regarding coverage for new technologies (and other limit setting decisions) and their rationales must be publicly accessible

(2) Relevance condition: these rationales must rest on evidence, reasons, and principles that all fair minded parties (managers, clinicians, patients, and consumers in general) can agree are relevant to deciding how to meet the diverse needs of a covered population under necessary resource constraints

(3) Appeals condition: there is a mechanism for challenge and dispute resolution regarding limit setting decisions, including the opportunity for revising decisions in light of further evidence or arguments

(4) Enforcement condition: there is either voluntary or public regulation of the process to ensure that the first three conditions are met.<sup>6</sup>

The approach taken by the Cambridge and Huntingdon Health Authority met some but not all of these conditions. For example, the application of a set of values to the Child B case met the relevance condition, but the way in which the authority's decision was communicated only partly fulfilled the publicity condition. On the latter point, more effort could have been made to explain the basis of the decision not to fund intensive treatment in advance of media attention. Similarly, the appeals condition was not met in that there was no mechanism for challenge and dispute resolution other than a request to the health authority to reconsider its decision. The absence of such a mechanism meant that legal action was the only formal recourse available to the Bowen family. The enforcement condition was met through judicial review of the health authority's decision, but the restrictive scope of such reviews in the English legal system meant that only some aspects of the process proposed by Daniels and Sabin were scrutinised by the courts. In particular, the courts looked only at the health authority's decision making process and did not require an explanation or justification of the decision or an assessment of the evidence on which it was based.

Taking the analysis further, Daniels and Sabin contend that one of the effects of making public reasons for funding decisions would be to establish a body of case law. As they state: "A commitment to the transparency that case law requires improves the quality of decision making. An organisation whose practice requires it to articulate explicit reasons for its decisions becomes focused in its decision making." The potential benefits include not only increased accountability for decision making but also greater consistency in the decision making process.

### Quasi-judicial features in health care

To make these points is to underline the parallels between decision making processes in health care and in the legal system. Hadorn has drawn these parallels

in the United States context in a way that reinforces the conclusions of this analysis. He notes that "the need to make relatively consistent case-by-case decisions amidst profound complexity is clearly one of the forces that has driven the health care system to adopt quasi-judicial features."<sup>8</sup> Hadorn argues that consistent procedures need to be adopted in health care, and he contends that these procedures should be centred on the consideration of evidence concerning the outcome of care and the formulation of judgments based on this evidence. Continuing the analogy with the legal system, Hadorn says that judgments should be based on a standard of proof that might be more or less stringent depending on the availability of resources and the views of policy makers. The point emphasised here is that "in the selection of a standard of proof . . . the fundamental balance between individual claims of need (that is, pursuit of individual good) and the greater public good is achieved."<sup>8</sup>

Applying this argument to the Child B case, it could be argued that the Cambridge and Huntingdon Health Authority considered the evidence concerning outcomes, and decision makers in the authority used their judgment to arrive at a decision based on this evidence. In the process, the consideration given to the probability of intensive treatment being successful was an attempt to apply a standard of proof to the case.

## Conclusion

While it is always hazardous to generalise from individual experiences, the case of Child B attracted such widespread attention and illustrated so many of the dilemmas of decision making in the health service that it would be an oversight not to seek to learn from it and to provide lessons for those who may be faced with similar dilemmas in future. Many issues emerged, but I have concentrated on the ethics of priority setting and the process of decision making. In relation to ethics, while the case seemed to illustrate the conflict between utilitarian considerations and the rule of rescue, the lack of an effective treatment, coupled with concern that the act of

rescue would do more harm than good, meant that the health authority was able to use the values it had adopted to refuse to fund other than palliative care. With regard to the process of decision making, we have noted how aspects of the process could have been strengthened, most obviously through the giving of reasons for the decision and the establishment of an appeals mechanism. The reason for emphasising the need to improve the process of decision making is that cases of this kind are always likely to generate debate and disagreement. What therefore matters is to structure the debate to enable different points of view to be articulated; to promote transparency and consistency in decision making; and to build trust, confidence, and legitimacy in the process. In the longer term, these characteristics of due process in decision making should enhance public understanding of choices in health care and promote more informed discussion of the issues. These lessons need to be acted on by health authorities and primary care groups.

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## A memorable moment

### Love and respect after 30 years

Footballers were playing in the field just over the neatly clipped hedge from the cemetery, their shirts uncomfortably brash against the faintly blue Lincolnshire sky, their imprecations and oaths almost swept away by the customary wind. Sue and I tended my parents' grave, briskly brushing the accumulated green stuff from the headstone. We stood back to look at the now much cleaner headstone. An old man I had noticed in the distance came past pushing his bicycle, the front basket tied on with baler twine. He joined us in contemplating the gravestone. Unprompted, he spoke:

"He was a very nice man, that doctor, and a very good doctor. He came to us when we was at Heckington, to my missus and me. He used to sit down and, well, just be able to talk to you, like. He cured my bad leg really well. He was real good to us. Doctors today they just give you a load of pills, not like him."

I noticed the stereotyped and possibly justified criticism of my colleagues; did it include me? I also remembered from time to time in my early childhood going out with my father on his rounds in one of a succession of black Wolseley cars to fistfuls of house calls; perhaps this had been one of them.

"I've just been tending the missus's mum's and dad's grave," he added. "If I've got some flowers left over I often put some on the doctor's grave."

Then I told him that I was the doctor's son and that I, too, was a doctor, working in Hampshire. He asked me if I was thinking of coming back. I said not, and perhaps imagined some disappointment in his eyes. I thanked him for his kindness; and then I wondered about the sort of person and the sort of professional who generates such respect and love that 30 years after his death old weathered men in fingerless gloves are putting flowers on his grave.

Terry Cubitt general practitioner, Alton, Hampshire

We welcome articles of up to 600 words on topics such as A memorable patient, A paper that changed my practice, My most unfortunate mistake or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to.