Media coverage of the Child B case

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See editorial on rationing and pp 1591, 1593, 1604

The case of a girl with leukaemia, known as Child B, hit the headlines in March 1995 when her father refused to accept the advice of doctors who counselled against further treatment and took Cambridge and Huntingdon Health Authority to court for refusing to fund chemotherapy and a second bone transplant for her in the private sector. British national newspapers varied greatly in the way they covered the case. Some paid little attention to clinical considerations and presented the case as an example of rationing based on financial considerations. Their selective presentations meant that anyone reading just one newspaper would have received only limited and partial information. If members of the public are to participate in debates about treatment decisions and health care rationing, means other than the media will need to be found to inform and involve them.

Some form of rationing is inevitable in a cash limited health service.[1] The issue of rationing, however, has most often been brought to public attention by media coverage of specific instances in which individuals have been denied treatment. One striking example was the case of a girl with leukaemia, known as Child B, which hit the headlines in March 1995.

Most people only became aware of the Child B case because of the media coverage it attracted. Media presentations of the case are likely to have shaped public perceptions of the way treatment and funding decisions are made in the NHS. The questions of whether further chemotherapy and a possible bone marrow transplant were in Child B's best interests, and whether the NHS should fund them, were highly complex and could be viewed from a variety of perspectives. This paper illustrates how British national newspapers varied in the way they selectively reported relevant issues and arguments in the early stages of the case. A more comprehensive account of a broader study of media coverage, extended over a longer time period, is forthcoming.[2]

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The public face of Child B (Jaymee Bowen)

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Outline of the case

Child B, whose identity was originally concealed by court order to protect her from the knowledge of how ill she was, recovered from acute lymphoblastic leukaemia diagnosed when she was 5 but later developed acute myeloid leukaemia. In January 1995, when she was 10, NHS consultants at both Addenbrookes and the Royal Marsden hospitals said that she had about eight weeks to live and that the only possible treatment, intensive chemotherapy and a bone marrow transplant (which would be her second) was very unlikely to succeed and was not in her best interests. Her father did not accept this and sought opinions from other doctors in Britain and the United States. He found a consultant in London, Peter Gravett, who was prepared to treat his daughter in the private sector, but Cambridge and Huntingdon Health Commission (the health authority) refused to grant an extracontractual referral for the £75 000 treatment. Child B's father challenged this refusal in the High Court, which ruled on 10 March 1995 that the health authority should reconsider its decision. However, Appeal Court judges later that day overturned the ruling and said the decision had been made rationally and fairly.

The case attracted much publicity, and an anonymous private benefactor paid for the treatment B's father wanted. Intensive chemotherapy met with only limited success, so Dr Gravett decided against a second bone marrow transplant and treated child B with an experimental treatment, donor lymphocyte infusion. She went into remission and survived longer than doctors had predicted. In October 1995, her father went back to court to get the identification ban lifted so he could publicise her case to raise money for further treatment. Child B was revealed as Jaymee Bowen, and further publicity followed.

The newspaper sample

To assess the coverage, we chose and analysed a sample of newspapers. Eight daily national newspapers—the *Daily Express, Daily Mail, Daily Mirror, Daily Telegraph, Guardian, Independent, Sun,* and *Times,* together with their Sunday equivalents—were included in the study. They represent a spectrum of reporting styles and political allegiances. We retrospectively searched issues from 10 March to 15 March 1995 (the period around the original court cases) for articles that were primarily about the Child B case and articles that covered a related issue or case and were printed as part of a spread of articles about Child B. We read each of these articles and systematically noted quotations or points relevant to particular aspects of the case. Further details of the methods are available elsewhere.[2]

We found 149 relevant articles, an average of over 18 per newspaper for the six day period. The case made front page news and was the subject of editorial

Box 1—Position of newspaper editorials with respect to the health authority's decision not to fund the treatment proposed for Child B

Daily Express—Non-committal. There is a moral dilemma. There is no certain answer to the question of whether child B would benefit from treatment. The issue of treatment cost cannot be ignored

Daily Mail—Non-committal. The decision was instinctively shocking, but sometimes decisions between patients will have to be made

Mail on Sunday—Implied the decision was wrong. Money in the NHS is wasted on fripperies

*Daily Mirror**—The decision was wrong. It was based purely on money

Daily Telegraph—The decision was sound, and the appeal court judges were correct to uphold it. However, the decision would be better understood if the NHS did not waste so much money

Sunday Telegraph—Implied the decision was wrong. It caused understandable anguish. Less NHS money should be spent on abortions (death) and more on last chances of life

Guardian—Implied the decision was right. The case is emotional, but "a rational health service is as important as a national health service"

Independent, Independent on Sunday—The decision was difficult. Sometimes it will not be appropriate to give last chance treatments which cause suffering to children.

Observer—Implied the decision was wrong. Parents' views should dominate. Although hard decisions must be made, people want them to be made with sympathy and understanding, not on the crude market principle. Most people would have said in this case let her have the treatment

Sun†—The decision was wrong. It reflects an inappropriate emphasis on money in the NHS and inappropriate priorities in terms of NHS expenditure

News of the World—Ambiguous. Took the position that it was a good thing that child B would get treatment, and argued that all parents would understand and admire B's father's actions. On the other hand, argued that life and death decisions should be made by doctors

Times—The grounds for the decision were unclear. If it was a decision not to subject a child to needless futile suffering, it was appropriate, but cost considerations have confused the issue

*The *Daily Mirror* included two editorials about the child B case in the study period.
†The *Sun* included three editorials about the child B case in the study period.

comment at least once in all the newspapers studied. It also attracted "in depth" coverage, with most newspapers publishing spreads of articles covering various aspects of the case. The *Daily Mirror* and *Sun* both "adopted" the cause of Child B and ran appeals named after her to raise money for leukaemia research.

Editorial stances

The newspapers adopted some strikingly different editorial stances towards the case, varying in their judgments about the correctness of the health authority's decision (see box 1) and interpreting the significance of the case in a range of ways. Leaders in the *Daily Mirror* and *Sun* started from the position that Child B "needed" the treatment and found it wholly unacceptable that she would not be given it by the NHS. They presented the health authority's decision as quite simply wrong and implied it was reached because financial considerations had been allowed to dominate—an indication of the sorry state of affairs prevailing in the NHS. (This was consistent with the *Daily Mirror*'s tendency, in recent years, to give a high profile to incidents such as ward closures and delays in treatment and present them as indicators of deterioration within the NHS and the failings of the current Conservative government). A selection of quotations in box 2 illustrates the position of these two tabloids.

Leaders in other newspapers more readily acknowledged the complexity of the case and considered some of the issues it raised regarding treatment and funding decisions. Relatively few, however, focused on the issue of whether the proposed treatment was in Child B's best interests and questioned whether it was effective and appropriate for her. Only five out of 16 editorial articles (in the *Daily Express*, *Guardian*, *Independent* and *Independent on Sunday*, and *Times)* mentioned the possibility that it might cause more harm than good, or acknowledged that most medical experts felt it was not the best course of action. The *Daily Telegraph* slightly ambiguously reported: "In the case of child B, doctors felt that the suffering she would undergo in the course of further treatment, and the unlikelihood of her surviving it, made the expenditure unwise."[3]

The basic positions adopted in leader articles were generally reflected in the news reporting of each paper. Opposing viewpoints were included but tended to be marginalised, appearing on letters pages, in columns, or as other first person opinion pieces.

OPPORTUNITY COSTS

The *Times* reported that the precise grounds for the Health Authority's decision were not clear, and commented that: "While subjecting a dying child to needless futile suffering would strike most people as undesirable, refusing treatment on the ground of cost is more difficult to accept."[4] Other editorials were more certain that costs had played a part in the health authority's decision, and most discussed the case at least once in the context of how money was spent within the NHS. However, they did this in two rather different ways.

The broadsheet editorials, with the exception of the *Daily Telegraph* and *Sunday Telegraph*, implicitly accepted that the concept of opportunity costs supported the argument for not treating Child B, assuming that the money could and would be spent on more effective treatments which would bring greater health gain than the one proposed for her. The *Daily Express* also explicitly stated: "Resources used on the little girl cannot be used on other cancer sufferers, including those whose chances of responding to treatment, and thus survival, are greater."[5] The *Daily Telegraph* defended the health authority's decision as correct because it was based on medical advice but felt that "public understanding of this dilemma would have been better were the NHS not perceived as inefficient and bureaucratically arrogant. It is harder to defend the decision not to treat child B when one hears of the spending spree on the administration of the NHS."[3]

Editorials in the *Sun* and *Mail on Sunday* used the concept of opportunity cost to support the argument

Box 2—The *Daily Mirror* and *Sun* condemned the decision

Headline: Condemned by bank balance (*Sun*, 11 March)

"What state is this country in when a girl's right to life hinges on the size of a hospital bank balance?" (*Sun*, 11 March)

"The idea that the medical judgement of a health authority can be clouded by financial considerations is distasteful and obscene." (*Sun*, 11 March)

Headline: A price too high to pay (*Daily Mirror*, 11 March)

"Money is everything in health care today....A child's life now is worth only what a health authority's accountants are willing to pay for it." (*Daily Mirror*, 11 March)

"Her father believes she was never treated as more than a name or number. No sick child should be seen as a mere statistic. If they are, health authorities will inevitably take decisions about them based purely on money." (*Daily Mirror*, 13 March)

Box 3—Examples of less worthy uses of NHS funds cited by newspapers

- Administration and bureaucracy (*Mail on Sunday, Daily Telegraph, Sun*)
- Managers' cars (*Mail on Sunday, Sun*)
- Abortions (*Mail on Sunday, Sunday Express, Sunday Telegraph*)
- Cosmetic surgery, breast implants, tattoo removal (*Sun, Sunday Express*)
- Sex change operations (*Sunday Express*)
- AIDS campaign (*Mail on Sunday*), AIDS treatment (*Sunday Express*)
- Fraud by NHS staff (*Mail on Sunday*)
- Health education propaganda (*Daily Telegraph*)

that child B should have been treated on the NHS, presenting the treatment proposed for her as a better use of money than other current NHS expenditures. This theme recurred in several news and feature articles in other newspapers. Box 3 shows the uses of NHS funds thought to be less worthy than the proposed treatment for Child B. The irony of the fact that the costs of the court hearings were enough to pay for the contested treatment was also highlighted in several articles.

Box 4—Some estimates of success as reported in the *Guardian*

Mr Pitt claimed the chances of success, using statistics provided by Peter Gravett...were in the region of 2.25 per cent. Other figures quoted by Mr McIntyre suggested the chances were slightly higher. "Even if it's only in the order of 5 or 6 per cent, she has a significant chance of being cured." (10 March)

B's father consulted experts in Los Angeles and Orange County, in the United States. They suggested treatment might have an 18 per cent chance of success. (11 March)

Dr Gravett, a Harley Street consultant haematologist likely to be treating the girl, yesterday put the chances of success at 10-20 per cent. (13 March)

The specialist in charge of her care admitted yesterday there was only a 1 per cent chance overall of a successful outcome...."There is a 10 per cent chance of the initial remission, then a 10 per cent chance of the transplant working. There is only a 1 per cent chance of a successful outcome...," Dr Gravett said. (14 March)

Reporting of factors contributing to the decision

THE CHANCES OF SUCCESS

One of the arguments which the health authority used to support its position that further chemotherapy and a second bone marrow transplant were neither appropriate nor cost effective in this case was that the treatments had only a very small chance of success. Against this, Child B's father argued that any chance of survival, however small, was worth taking. Newspaper articles expressed varying degrees of sympathy with these arguments but rarely considered the difficulties of determining the probability of a favourable outcome at which treatments should be given.

Information about the likelihood of success of treatment was often confusing. A wide range of quantitative estimates was reported, but which outcomes they related to (cure or remission) was not always clear, and little consideration was given to the validity of the estimates, the degree of certainty attached to them, or their applicability to Child B. While it was clear that doctors' opinions varied, the reasons for this were not explored and the quality of available evidence about the effectiveness of the proposed treatment was rarely commented on. Box 4 illustrates something of the range of statements about the chances of success made over a four day period in one newspaper.

TREATMENT VERSUS PALLIATIVE CARE

The health authority argued that the proposed treatment would be "distressing" and might do Child B more harm than good. They said her best interests would be served by providing palliative care only. Her father basically argued that the possibility of adverse side effects was outweighed by the chance of survival which treatment offered. Again, newspaper articles varied in their propensity to accept these arguments, and placed different emphases on the possible side effects of treatment.

Many articles did not explicitly mention palliative care, and readers might have assumed that the alternative to chemotherapy and a second bone marrow transplant was no care at all. The only professional counters to the claim that palliative care was the best option were attributed to Dr Gravett and appeared in the *Daily Mail, Daily Mirror,* and *Independent.* Dr Thomas Stuttaford in the *Times* also said: "There is no evidence that a death from untreated leukaemia is likely to be appreciably easier than one from the complications of treatment. The determining factor in the comfort of any dying patient lies in the skill of the doctors and nurses looking after them."[6]

EXPERIMENTAL STATUS OF THE PROPOSED TREATMENT

In coming to its decision, the health authority considered the fact that further chemotherapy and a second bone marrow transplant had not been shown to be effective in cases like that of Child B. In a press statement it said the decision had been made "in the light of Department of Health policy to fund expensive new treatments only if they have been shown to be effective." The Appeal Court judges agreed that the treatment "did not have a tried record of success" and was "at the frontier of medical science."

The fact that the treatment was experimental rather than of proved benefit was explicitly reported in the *Daily Mail, Daily Telegraph,* and *Times.* The *Daily Mail* and *Times* also noted that the NHS doctors treating Child B claimed the proposed treatment would be "experimental rather than therapeutic." Although recent progress in treatments for leukaemia was briefly referred to by several articles, few mentioned that the treatment proposed for Child B might be justified if it was given as part of a research programme to evaluate its effectiveness, thus contributing to knowledge of how best to treat people with her condition. The *Guardian* alone reported the health authority's solicitor as arguing that the only basis on which the treatment could be justified was for experimental or research reasons.[7]

The *Daily Mirror* devoted an article to leukaemia research which attributed current leukaemia cure rates to "brilliant research" and said that it was only through further research that better combinations of drugs and ways to reduce their side effects would be found.[8] It described how "the 20 major centres treating childhood cancer throughout Britain work together in the UK Children's Cancer Study Group" and argued that "coordinated research is essential" but made no mention of the fact, reported in a few other papers, that this group had advised against treating Child B, and that she would receive her further treatment outside it.

Treatment decisions

The Child B case led to some consideration in the media of who should make decisions about whether to treat seriously ill children, although newspaper coverage very rarely mentioned that it is now NHS policy to promote patient choice in health care.[9] The importance of both medical expertise and the views of the child and family in individual treatment decisions were emphasised, and in many articles some form of shared decision making was implicitly advocated. However, there was little practical advice as to what should be done when doctors and parents disagree, as happened in this case.

The rarity of the kind of explicit challenge to medical expertise which B's father made was scarcely commented on. The admiration expressed in some newspapers for his actions implied that such challenges are sometimes desirable or necessary. This has possible implications for professional-patient relationships and the therapeutic possibilities of these. Media coverage of the Child B case highlighted the fact that doctors sometimes disagree and questioned the extent to which people should have confidence in doctors' advice. It could make people suspect that when doctors advise against treatment, they are motivated by cost considerations rather than by concern to do what is best for the patient. Readers could also have been alerted to the possibility that doctors might sometimes be overruled by health authorities in decisions about expensive treatments. (Doctors' roles as patients' advocates were only rarely mentioned). However, we can only speculate about the effects of this sort of coverage.

A few articles suggested that media coverage of the Child B case could have the effect of reducing the trust which people put in doctors. For example, the *News of the World* featured the parents of a girl who had died of leukaemia. They were said to be "tortured with guilt" after hearing of Child B's father's fight for further treatment for his daughter. The father was quoted as saying: "I keep asking myself if they let Sharon die because of money as well. B's father had the guts to find out why they were stopping her treatment. I didn't. I never questioned it. I accepted it. But it makes me feel now that if I'd done what he's done would I have got the same answer, 'We can't afford it'? It's really bugging me. Did I let my daughter die without at least finding out what chance she had and what I could do about it? ... You accept what the doctors tell you because they are the experts and you trust them. Now I can't help asking if I did the right thing."[10]

Although many reports of the case made it clear that doctors' opinions could vary, there was little explicit consideration of how to judge which doctors are right. The fact that people will probably always be able to find a doctor willing to provide the treatment they want as long as they are able and prepared to pay was occasionally referred to, but neither the possible harms nor the inequity of this attracted much comment.

The imperative to do something for a dying child

Much of the news reporting of this case was consistent with the expectation that something can and should be done to prevent a child from dying. The fact that this case involved a dying child was played up, particularly in the tabloids. Child B's age was mentioned in the vast majority of reports, and the *Sun* dubbed her "Little B" or "Little miss B."

Several articles noted that many people instinctively felt that Child B should be given treatment, reflecting widespread reluctance to accept that children sometimes die and a general sentiment that it is better to try something than do nothing. Some more considered pieces acknowledged the emotional pressures to try any treatment that was available but argued that when all the risks, benefits, and uncertainties of the treatment were considered, the hard decision not to treat might need to be taken.

"When a child falls ill with a potentially fatal illness," said one journalist, "parents naturally wish to do everything possible, and they fear that they will feel guilty later if they do not. There can be no hard rules about whether to intervene or let nature take its course. Each case must be judged on its own merits, but doctors have a moral responsibility to advise against treatment if it will only prolong suffering."[11]

The tendency to attach more sympathy to children and be inclined to treat them preferentially was only rarely analysed. A few newspapers commented on the possibility that if health care rationing is done through the media and public sympathy votes, then primacy will often be given to children, whether this is appropriate or not.

Much newspaper coverage reflected the sentiment that all possible technologies should be tried and, at least in "deserving" cases, they should be provided by the NHS. The media accepted with little comment that when the NHS "failed" to provide these technologies, people would seek them privately and would do what they could to raise the money.

Health care rationing

While all the newspapers reported at least once the health authority's argument that its limited resources could be better spent than on Child B, further discussion of the general issue of health care rationing was largely confined to the broadsheet newspapers. Most articles that addressed the issue accepted that some rationing was inevitable, even if they disapproved of the decision made in Child B's case. They frequently pointed out that rationing decisions were not a new phenomenon to health care but the public had simply not been aware of them until recently. All four broadsheets argued that the question of how health care should be rationed warranted public debate. They tended to advocate greater public participation in prioritisation decisions, although a *Daily Telegraph* leader insisted, "It is right that doctors should determine who benefits because they have clinical

Box 5—How the newspapers saw the child B case in relation to rationing

The appeal court's decision has implications of huge importance. It has underpinned the health authority's right to take costs into account in deciding whether to treat patients. (*Daily Mail*, 11 March)

The case has brought into sharp and public focus the simple, central truth of modern state-provided medicine. The National Health Service cannot possibly afford what is now medically possible. (*Independent*, 11 March)

These latest examples raise fears that rationing of life saving resources is not just creeping into the NHS but is already entrenched. (*Daily Telegraph*, 11 March)

This case has raised in acute form the thorny question of priority setting in the NHS, where limited funding meets potentially limitless demand. (*Independent on Sunday*, 12 March)

Medical decisions have always been about money, but for the first time those (making) judgments are being brought face to face with what they cost, not in the privacy of the consulting room but in the transparency of open court. (*Sunday Times*, 12 March)

There has always been rationing in the NHS; waiting lists were and are one way of eking out limited funds. The difference now with a market operating within the NHS is that the decisions are becoming more transparent. (*Independent*, 11 March)

expertise."[3] However, they made few practical suggestions as to how this was to be done.

The publicity surrounding the Child B case brought health care rationing to public attention and highlighted (with occasional dissent on this point) the fact that the NHS cannot afford to provide every possible medical technology to everyone who wants it. Again, there were few constructive suggestions as to how decisions should be made about whom to treat. A selection of comments about the significance of the Child B case in this respect is provided in box 5.

Towards an informed public debate?

Decisions about the treatment of seriously ill children and the rationing of health care are both complex and emotive. This study examined the extent to which the media informed the public about the various issues associated with a particular case. Although many issues and arguments were discussed in one or other newspaper article, people who dipped into or read only one newspaper would only have found a very partial view. Publicity brought the case and some of the issues it raised into the open, but it did not necessarily leave people well informed. In particular, the question of whether the treatment was in the child's best interests was relatively neglected. Child B became "the girl refused treatment on the NHS" and her case was quite clearly associated in early media coverage with health care rationing.

Journalists have to work within severe time and space constraints and must write entertaining stories that sell newspapers.[12] We should not expect them to provide a comprehensive and detailed analysis of all the relevant aspects of a case like this. The current climate, in which the NHS is highly politicised, means that even cases that are primarily about clinical effectiveness and a patient's best interests come to be seen as examples of rationing.

Public participation in debates about health care rationing is increasingly seen as desirable.[13] However, given the limitations of the media, other means will need to be sought if the public are to participate in an informed way.

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Setting priorities: is there a role for citizens' juries?

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Citizens' juries are an attempt to meaningfully involve members of the public in decisions which affect them in their own communities. The Institute for Public Policy Research and Cambridge and Huntingdon Health Authority have recently piloted the first jury in the United Kingdom. Sixteen jurors sat for four days, hearing evidence from a number of expert witnesses. The jurors were asked to consider how priorities for health care should be set, according to what criteria, and to what extent the public should be involved in this process. This pilot was also an attempt to assess the process itself, and our initial evaluation indicates that, given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care.

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One sixth of health authorities are now explicitly excluding certain treatments from public provision.[1] Who is making these decisions, and according to what criteria? What opportunities do the public have to challenge or be involved in these decisions? As Anne Bowling has pointed out, obtaining a representative view from the public can be difficult, and the methodology of ranking lists of treatments and services can be criticised as superficial in relation to the complexity of the decision to be made.[2] The Institute for Public Policy Research in partnership with Cambridge and Huntingdon Health Authority has recently piloted the first citizens' jury in the United Kingdom in an attempt to develop a more sophisticated technique for involving the public in these difficult decisions.[3]

Methods

Professional recruiters (Opinion Leader Research) were given a demographic breakdown of the Cambridge and Huntingdon area, and 16 people were selected by stratified random sampling to represent their community. The jury sat for four days, and during this time the members were presented with information to help them to reach a number of decisions. Jurors were asked to consider how priorities for purchasing health care should be set, according to what criteria, and what role, if any, the public should have in these decisions. Expert witnesses gave evidence, and jurors were given the opportunity to question them before debating the issues among themselves. All of their discussions were recorded, and jurors were asked to fill in questionnaires before and after the event on issues of health policy, both as individuals and as a group, so that we could obtain some quantative and qualitative data.

Results

The citizens' jury heard evidence from Ron Zimmern, director of public health at Cambridge and