The role of doctors, patients and managers in priority setting decisions: lessons from the 'Child B' case

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Abstract

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The difficulties in treating patients with life threatening illnesses were highlighted by the case of Jaymee Bowen, a 10-year-old girl with leukaemia who was refused funding for a second bone marrow transplant in 1995. Jaymee's case was widely reported at the time and came to epitomize the dilemmas of rationing in the United Kingdom's National Health Service. In reality, the paediatricians who had cared for Jaymee based their decision on clinical rather than financial considerations, and the media reporting of the case failed to reflect the complexities of the issues involved. The case also demonstrated the difficulties of determining the best interests of children and of obtaining their consent to treatment. There were disagreements between Jaymee's father and the paediatricians who had treated her about how her best interests could be served and this led to a breakdown of trust and the search for further opinions. This highlighted the rise of consumerism in health care and the challenge to doctors and managers to justify their decisions and to give reasons for these decisions. The common theme in Jaymee's story is the need for greater openness in decisions on priority setting and stronger safeguards for patients.

The case of Jaymee Bowen, more commonly known as 'Child B', has come to epitomize the dilemmas of rationing in the UK's National Health Service (NHS), defined here as the denial of effective treatment on cost grounds. The decision of the Cambridge and Huntingdon health authority not to fund a second bone marrow transplant for Jaymee in February 1995 became headline news and brought to public attention the difficulties involved in treating patients with life threatening illnesses. In Jaymee's case, the Health Authority followed the advice of the paediatricians who knew the Bowen family and who believed that palliative care rather than further intensive treatment was

the appropriate response to the return of her leukaemia following a bone marrow transplant carried out in 1994. The issues involved entered the public domain when Jaymee's father refused to accept this decision and took the Health Authority to court in an attempt to have it overturned. In so doing he invoked the support of two adult leukaemia specialists who had seen Jaymee and who were prepared to undertake further intensive treatment. The courts ultimately backed the Health Authority's decision and treatment was then provided in the private sector with funds made available by an anonymous donor. The doctor who cared for Jaymee decided not to undertake a second transplant

and instead administered an experimental form of treatment known as donor lymphocyte infusion. Jaymee survived for over a year after the court hearing but died in May 1996 following complications associated with her treatment.

Amongst the many issues raised by Jaymee Bowen's case, three are of particular significance. Firstly, the public presentation of the case as an example of rationing failed to reflect the full complexity of the decision making process. In particular, the opinion of the paediatricians involved – that clinical rather than financial considerations lay behind their decision to recommend palliative care – was never adequately reported in accounts of what happened at the time. Secondly, the case illustrated the difficulties of determining the 'best interests' of children when there is disagreement between doctors and parents. In the process, it raised major questions about the adequacy of current arrangements for obtaining consent from both children and siblings. Thirdly, Jaymee's story highlighted the rise of consumerism in health care and the challenge this posed for doctors and health service managers. Not least, it demonstrated the need to review communication between patients and their families on the one hand and doctors and managers on the other, and to ensure that the reasons for treatment decisions are well understood.

This paper draws on interviews with those involved in the case and analysis of relevant papers¹ to explore each of these issues in turn.

Rationing

Jaymee received a bone marrow transplant for the treatment of her leukaemia at the Royal Marsden Hospital in London in March 1994. Only 9 months later she relapsed and it was at that point that the paediatricians at the Royal Marsden and at Addenbrooke's Hospital in Cambridge (where she had been treated over a number of years) had to decide what further treatment was appropriate. In considering alternative options, the doctors involved were guided by Jaymee's medical history, including a prior malignancy, non-Hodgkin's lymphoma, diag-

nosed in 1990, and their experience of treating children with similar medical conditions in the past.

As a 10-year-old who had already received intensive treatment over a number of years, Jaymee was in poor health. At the time of her relapse she had limited bone marrow reserve and high levels of cardiac toxicity arising out of the chemotherapy she had undergone. Furthermore, experience of undertaking second transplants in children led the paediatricians to be cautious in proceeding down this route. Their experience was reinforced by data from the bone marrow transplant registries which showed that all patients with Jaymee's type of leukaemia who had been retransplanted had died. As one of the paediatricians put it:

I don't intend to have any more experience of second transplants within 12 months of the first because all four or five I've seen have been a disaster and afterwards the parents wished they hadn't agreed to their child having a second transplant. That's my database, that's how I make decisions. I won't go on doing treatments that I think are wrong for children or unkind to children (interview, 13 November 1996).

Another paediatrician emphasized that the decision to recommend palliative care for Jaymee rather than further intensive treatment was based on clinical rather than financial considerations. She drew a distinction between 'good death and bad death' (interview, 30 October 1996), arguing that chemotherapy and a second transplant were likely to involve considerable suffering for Jaymee. In view of the low probability of a successful outcome, palliative care was the preferred option as this would enable Jaymee to enjoy a higher quality of life than would otherwise have been possible for the remaining weeks she had to live. The argument of the paediatricians was that palliative care was a positive choice and was the appropriate treatment in the circumstances. Above all it would enable them to do more good than harm and would avoid the painful effects they had observed when intensive treatment had been undertaken in similar cases.

These views persuaded the Cambridge and Huntingdon Health Authority to reject the

request that chemotherapy and a second bone marrow transplant should be funded. The values adopted by the Health Authority to inform its decisions in cases of this kind laid particular emphasis on using resources effectively and appropriately. Although the adult leukaemia specialists consulted by the Bowen family felt that further intensive treatment was an option, and were more optimistic than the paediatricians about her chances of coming through such treatment successfully, the Health Authority was confident that the paediatricians, who had known Jaymee over a number of years, were best placed to take a holistic perspective on her care. In communicating this decision to David Bowen, Jaymee's father, the Health Authority's Director of Public Health stressed that it was based on clinical advice rather than the availability of finance. As he said in a letter (21 February 1995) to David Bowen:

Should there be any misunderstanding I should state quite clearly that any decision taken by the (Commission) will be made taking all clinical and other matters into consideration and not on financial grounds.

He also maintained that further intensive treatment would be considered experimental and that guidance from the Department of Health cautioned against the use of health service funds in this way.

Given this reasoning, how did the case come to be seen as an example of rationing? Finance entered the argument when the courts became involved. In an affidavit sworn for the purpose of the judicial review initiated by David Bowen, the Director of Public Health stated:

First and foremost I had to consider whether the proposed course of treatment was clinically appropriate for Jaymee. I also had to consider whether it would be an effective use of the (Commission's) limited resources, bearing in mind the present and future needs of other patients (affidavit, March 1995).

He continued:

The amount of funds available for health care are not limitless. The respondent has a responsibility to ensure that sufficient funds are available from their limited resources for the provision of treat-

ment for other patients which is likely to be effective (affidavit, March 1995)

As the judge who heard the case in the High Court commented at the time, the juxtaposition of these statements with the earlier argument that finance was not important 'amounted to something of a volte-face'.² The financial arguments were highlighted in the media reporting of the case and it was this that led Jaymee's experience to be represented as an example of rationing.

The Health Authority's chief executive, reflecting on the court proceedings after the event, expressed surprise at the attention given to finance in the courts. In his view, this occurred because the lawyers advising the Health Authority were willing to use whatever arguments were necessary to win the case. As a consequence, it was difficult to maintain the position that Jaymee's case was simply about what care was clinically appropriate. In any event, the Health Authority itself acknowledged – in a review of its experience prepared for the NHS Executive – that costs could not be ignored, and that the substantial expenditure involved coupled with the low probability of success resulted in its decision not to fund treatment. In adopting this line, the Health Authority was taking into account its responsibility to weigh the needs of one individual against those of the wider community and was recognizing that from its perspective finance was a factor in the decision making process; albeit not the most important one. This illustrated the inherent tension between individual and community interests, particularly when the amount of expenditure involved in treating one patient created significant opportunity cuts for others.

The paediatricians involved expressed anger at the way in which the debate about Jaymee's treatment was transformed into a discussion of rationing. They were particularly critical of the Director of Public Health for building an 'academic rationing discussion' out of the case and in their view distorting the central issues in the process. Against this, the reluctance of the clinicians themselves to engage in public debate of the issues undoubtedly contributed to the partial

reporting of the case. At least one of the paediatricians wondered in retrospect whether he had done the right thing. His view was that the clinical arguments for not proceeding with further intensive treatment, including the balance between risks and benefits, might have been better understood if he had participated in the debate. His fellow paediatricians did not share these doubts, arguing on the basis of bitter experience that the media was unlikely to give doctors' views a fair hearing in an emotive case of this kind.

The lesson that emerges is the difficulty of conveying the full complexity of decisions involving the treatment of patients with life threatening illnesses. As Entwistle and colleagues have commented in their analysis of the media handling of the case:

Our study suggests that while the media may raise awareness of the issues which need debating, and may influence people's perceptions of these issues they do not provide the solid base of information which would allow people to participate in debates in a particularly informed way, and their coverage of itself does not constitute a full public debate.³

This is largely due to the fact that the selective reporting of the case by the media failed to explain adequately the dilemmas confronting clinicians and the family, and demonstrates the distance yet to be travelled in enabling the public to understand the subtleties of clinical decision making, including the reliance on probabilities rather than certainties in advising on treatment options. It also indicates the tendency of the media to simplify complex issues and to downplay the complications that confront decision makers in the NHS. The fact that the Health Authority considered the cost of treatment as one factor in the decision undoubtedly contributed to this and meant that the clinical arguments received less attention.

Best interests

Closely linked to the issue of whether Jaymee's treatment was based more on clinical than financial considerations is the question of who should determine her best interests? Throughout

the later stages of Jaymee's illness, David Bowen sought to protect her from full knowledge of her condition and prognosis. Only when the anonymity order was lifted in October 1995 did Jaymee realize that she was Child B. David Bowen chose to keep Jaymee in ignorance of the full facts in the belief that the chances of a successful outcome would be enhanced by keeping her happy and feeling positive. This was based on his reading of the medical literature and his assessment that treatment outcomes were influenced in part by the psychological state of the patient.

In taking this line, he adopted a truly paternalistic approach, but this troubled the paediatricians. Their view was that a child of Jaymee's maturity should have been involved in decisions on treatment options. As one of the doctors commented:

This case is unusual because David Bowen was not involving what he called a very grown up 9-year-old from taking part in the discussions when she always had been included prior to her relapse. He assumed that because she was his daughter she would have the same views as him, that she wanted the treatment even though it only had a small chance of a cure. And that was an assumption that a father is not entitled to make (interview, 13 November 1996).

The response of the paediatricians was to take particular care themselves to assess Jaymee's best interests and to advise accordingly. It was this that led them to recommend palliative care rather than further intensive treatment. As another paediatrician said in her affidavit to the courts:

I took the view that it would not be right to subject B to all this suffering and trauma when the prospects of success were so slight (affidavit, March 1995).

The adult leukaemia specialists who saw Jaymee took a different view. They argued that, unlike the paediatricians, they were approaching Jaymee as a mature child and on this basis were responding positively to David Bowen's wish to access further treatment for his daughter. Drawing a contrast between himself and the paediatricians, one of these specialists commented:

They were treating her as a small child and I was treating her as a young adult. I think there is a difference in style between paediatricians and adult haematologists. I saw her as a young lady who had a life to live and who had got enjoyment out of her current life. They were seeing her as a small child (interview, 10 January 1997)

What mattered to the adult specialists was the courage Jaymee had demonstrated in undergoing intensive treatment in the past and the strong desire of David Bowen to persuade doctors to undertake a second transplant. Being more accustomed to dealing with adult patients able to make decisions themselves, they were more willing to accept David Bowen's views as proxy for his daughter's and were less concerned at the potential harmful effects of the treatment he was seeking. These specialists also felt less constrained by the guidelines and protocols observed by the paediatricians and were therefore prepared to offer a different opinion on treatment options.

Underlying these issues is the question of how consent to treatment should be sought in cases of this kind. The law on consent to treatment by children gives parents the responsibility to decide what should be done, except where children are of the age or maturity to understand the options and arrive at decisions.⁴ As a 10-year-old widely recognized as mature at the time she relapsed, Jaymee was on the borderline in this respect. And even accepting that in practice:

The solution has been to allow parents or guardians to supply the requisite consent.⁴

It has been argued that:

This still leaves open the crucial question of how best interests of the child are to be determined, particularly where parents want to make risky choices for their children, or include them in research.⁴

Jaymee's case fell into precisely this category given that the intensive treatment options under consideration were not accepted as standard therapies. The Children Act 1989 does not give children rights to make independent decisions about medical treatment and under the law it is a matter for parents to decide. In this context, guidelines for the ethical conduct of medical

research involving children drawn up by the Royal College of Paediatrics and Child Health note:

Parental consent will probably not be valid if it is given against the child's interests. This means that parents can consent to research procedures which are intended directly to benefit the child, but that research that does not come into this category can only be validly consented to if the risks are sufficiently small to mean that the research can be reasonably said not to go against the child's interests.⁵

More recent guidelines issued by the College state:

The wishes of a child who has obtained sufficient understanding and experience in the evaluation of treatment options should be given substantial consideration in the decision-making process.⁶

Whilst acknowledging the complexities that arise in this area, it does appear that David Bowen, in exercising the judgement accorded to him under the law, did not involve Jaymee as much as he might have done. Similar considerations apply to Jaymee's younger sister, Charlotte, who acted as the donor for both the bone marrow transplant and the donor lymphocyte infusion, and who was persuaded by her father to take on this role. Reflecting on the difficulties involved in obtaining consent from children, Alderson and Montgomery propose a code of practice for children's health care rights, including a right to withhold consent to proposed treatment if children are competent to do so.⁷ In a similar vein the Royal College of Paediatrics and Child Health has argued that there should be a presumption of competence to give consent to treatment unless a child is obviously incompetent.⁶

In emphasizing the autonomy of children, these approaches turn the current position on its head and, if accepted, would have major implications for health care decision making. In practice, given the complexities raised by this and other cases, it is unlikely that any code of practice could be applied rigidly in all circumstances. What is important is to recognize the particular difficulties that arise when parents choose not to involve children in treatment

decisions, especially when the opinions of parents and doctors differ. In situations of this kind, there are strong arguments for offering greater protection to children, at the same time acknowledging the need for the exercise of judgement in individual cases. At a minimum, Jaymee's experience reinforces the need to review current arrangements for obtaining consent with the emphasis these place on the role of parents.

Consumerism

A central feature of this case was that David Bowen was prepared to take his dissatisfaction with the clinicians and the Health Authority to the courts. Yet before doing this, he sought to challenge the decision not to fund chemotherapy and a second bone marrow transplant by doing his own research into treatment options and consulting doctors around the world. By this stage, there had been a breakdown of trust between the paediatricians and the Bowen family and this led to the search for further opinions. As time was of the essence, David Bowen short circuited most of the standard routines, making his own arrangements to seek professional advice, using faxes and phones, and working long hours on Jaymee's behalf. One of the most important sources of help was the library at the Royal Society of Medicine in London. Initially, he had to pay £15 for a ticket to use the library but after that it was free and the librarians were very helpful.

David Bowen used the library's resources to learn about different types of leukaemia and research into treatment. As a result, he felt he was more knowledgeable about Jaymee's illness than some of the doctors responsible for her care. As he stated: '...oncologists are the general practitioners of the cancer world' (interview, 12 June 1997).

In making this comment Bowen was arguing that only those with detailed knowledge and experience of particular forms of leukaemia were in a position to advise on the latest treatment options. In his view haematologists were better equipped to treat Jaymee's cancer than paediatric oncologists. He therefore began a world-wide

search for help, contacting doctors in Europe, New Zealand, the United States and elsewhere.

David Bowen explained that he did this by reading books, using his brother who lived in the United States, and phoning doctors at home and in hospital. The fact that he needed little sleep, no more than 4 hours a night, was particularly helpful in making contact with specialists in other time zones. If he couldn't speak directly to them, he would explain the situation to their wives or secretaries, in the process winning their sympathy for a child's illness and ensuring that the phone calls were always returned. His search eventually led him to California where two specialists advised that a second transplant could be undertaken and they estimated a higher probability of success than indicated by their colleagues in the United Kingdom. David Bowen obtained the protocol used in California and recounted how he turned up with a sheaf of faxes and notes to see the specialists at the Royal Marsden. In acting in this way, David Bowen recognized that from the doctors' point of view,

I was being a pain in the arse (interview, 12 June 1997)

In the circumstances he felt he had no option, given the unwillingness of the paediatricians who knew Jaymee to change their minds. One of these doctors recalled, 'by the time I saw him this was a mission'. He added, 'he (David Bowen) was very angry; he argued with me for an hour' (interview, 13 November 1996). Another paediatrician emphasized how unusual this form of behaviour was, commenting, 'it is very rare to come across a father, a person, like this' (interview, 30 October 1996).

She added that there had been previous occasions on which David Bowen would 'cause an almighty scene' on the ward and in the hospital in order to get his way. This caused problems for both staff and other patients and affected how he was seen by those responsible for Jaymee's care.

The paediatricians involved in Jaymee's care acknowledged that although David Bowen exhibited a rare single-mindedness his actions exemplified the decline in deference in the

doctor-patient relationship and the demand on the part of parents for greater involvement in treatment decisions. As one paediatrician put it:

When I was 40 and I was a consultant and people actually accepted my judgement I was pretty amazed. I didn't tell them that. But I never felt very god-like as a doctor. Now, the trouble is if you're not a little bit god-like as a doctor you spend hours and hours discussing things with patients, so ultimately you have to say: look, you either accept my opinion or you don't, and if you don't like my opinion, go somewhere else (interview, 13 November 1997).

In the case of the Health Authority, David Bowen emphasized the value of the help he received from secretaries and junior staff – the 'little people' as he described them – who told him what to do and to whom to speak. He was much less happy with the staff who took the decision not to fund intensive treatment. The Director of Public Health adopted a policy of not meeting directly with patients and their families in cases of this kind and of relying instead on the advice and opinions of the doctors. This meant that at no time did he have direct contact with the Bowen family. David Bowen felt that this policy was 'just a waste of space' adding 'it did not go down well with me' (interview, 12 June 1997). The real problem he encountered was finding someone to help and advise when the views of doctors conflicted.

In this context the detachment of the Authority was a hindrance, simply adding to the problems faced by a father running short of time in a desperate search for a cure. A recurring theme in David Bowen's reflections on his experience is the inadequacy of communication between doctors and nurses on the one hand and patients and their families on the other. Virginia Bottomley, Secretary of State for Health at the time, felt that the one aspect of the case on which the Health Authority was vulnerable was its relationship with David Bowen. As she recalled during interview:

A more sensitive approach to the family with counselling and advice might have left the treatment in the NHS (interview, 22 July 1997).

Against this, some of the doctors felt that David Bowen's determination was a particularly important factor and that even the most sensitive approach would not have prevented him following the course he did. This view derived from their experience of dealing with him and their perception that he wanted to be 'in control' of events at all stages. We have noted that the paediatricians in particular were worried that this worked against the interests of Jaymee and her sister, Charlotte, as well as being difficult for them to handle.

What is clear is that patients and their families increasingly expect to receive a full explanation of the available options and the reasons why some alternatives are preferable to others. A similar point is made by Daniels and Sabin in their analysis of the funding and provision of new technologies in managed care organizations in the United States. These authors note that 'reason giving' is especially important in decisions on new technologies where patients have run out of standard treatment therapies. They note that in these cases:

...the limits set by the organization are widely perceived to be cost-driven or overly paternalistic. To the desperately ill patient, the organization may appear to be denying a 'last chance' just to save money... Reason-giving assumes special importance in these highly charged situations.⁸

These arguments apply with equal force to health authorities and other bodies charged with responsibility for priority setting in the NHS. Although there may be no statutory duty on health authorities to give reasons for their decisions, the process of priority setting might be enhanced if this were to happen. At the very least, it would allay fears that these decisions are motivated by financial considerations alone, fears which may have been accentuated by the increased involvement of managers in priority setting. More positively, by placing an obligation on decision makers to explain the rationale behind their choices, it would promote rigour and consistency in priority setting as well as enhancing public understanding of the issues involved. This is particularly important given the confusion we have noted about the respective

role of financial and clinical considerations in this case. Together with a means of appealing against decisions, reason giving would be one way of retaining support for public agencies at a time when patient and public expectations are rising.

Conclusion

Drawing firm conclusions from individual cases is a hazardous enterprise. Nevertheless, the story of Jaymee Bowen illustrates both the practical and ethical dilemmas involved in decisions on the treatment of patients with life threatening illnesses, and it indicates areas in which current arrangements are inadequate. This paper has focused in particular on the public presentation of the case, the difficulties in determining the best interests of children and of obtaining their consent to treatment, and the challenge posed by the rise of consumerism in health care. In so doing, it has demonstrated that parents are becoming increasingly assertive in acting as advocates for children and in wishing to participate in treatment decisions. At the same time, the case has highlighted the difficulty of determining the views of children (as opposed to parents) about their treatments and the need for stronger safeguards to protect their interests. Jaymee's story indicates the formidable obstacles facing governments in engaging citizens in priority setting, especially given the partial reporting of the case by the media. Above all, it shows that the demand for health care is likely to increase as expectations of medicine rise and as patients and those acting as their advocates seek out information about treatment options and use this information to challenge the advice they are given.

In highlighting the clash between medical paternalism and consumerism, Jaymee Bowen's case presents a compelling case for strengthening the process of priority setting in the NHS. Implicit decision making by clinicians has predominated for most of the last 50 years but is increasingly being challenged by patients and the

public. It is also under threat from managers as a result of the establishment of health authorities as purchasers of services for local communities. With the genie out of the bottle, the argument for establishing fair and transparent mechanisms for resolving choices in health care is compelling. If the lessons to emerge from Jaymee's experience can be acted upon, then her tragic life and death will not have been in vain.

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