



Whitefield BRIEFING

July 1998 (Vol.3 No.3)

Health Care Ethics: The Child B Case A Proposed Framework for Moral Decision-Making

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Being a Christian involves wrestling with difficult ethical issues and decisions, and finding a means of responding to them in appropriate, biblical ways. One area where this struggle is evident is within health care. Society is pervaded by complex issues such as abortion, euthanasia, genetic engineering and resource allocation. This final issue has significant consequences for all of us in society. As Christians we are entrusted with these resources and expected to use them responsibly. Yet, precisely how this is best achieved is not always clear. One example of an highly publicised and complicated case of resource allocation focused on Child B.

THE CASE

In May 1995 the Child B case received much attention within health care and wider society.¹ Jaymee Bowen was a ten year old girl with leukaemia. She had been treated for and recovered from leukaemia at age five and was now given approximately eight weeks to live. The proposed aggressive treatment included further chemotherapy, costing £15,000 and a second bone marrow transplant, costing £60,000. Upon advice from the National Health Service clinicians treating Jaymee, the Cambridge and Huntingdon Health Authority refused to fund treatment, and opted instead to provide palliative care. Jaymee's parents disagreed and took the health authority to court. Ultimately, Jaymee received private treatment, went into temporary remission and eventually died in May 1996.

DIFFERENT PERSPECTIVES

Part of the primary conflict surrounding this case was due to the differing perspectives involved. The NHS doctors and nurses viewed this treatment as not being in her best interests because of the very small chance of its success, the experimental nature of a second bone marrow transplant, and the additional pain and distress it would cause her. Jaymee and her parents viewed the aggressive treatment as being in her best interests and seemingly wanted to pursue the chance of cure at all costs. The health authority agreed with its clinicians' judgment, as well as being aware of the cost of the treatment and its wider responsibility to other patients. In contrast, the private sector was willing to provide treatment on request.

From the legal perspective, the High Court ruled that the health authority had not considered sufficiently the views of the parents, was inaccurate to refer to a second bone marrow transplant as 'experimental', and had wrongly considered the cost to be £75,000 when the initial cost was only £15,000. This court urged the health authority to reconsider its decision, but did not require it to fund further aggressive treatment. The Appeal Court overturned this judgment. Significantly, it stated that the courts were not the place to decide between conflicting medical opinions and that the health authority had rightly considered how to use resources to the advantage of a maximum number of patients.

A FRAMEWORK FOR ANALYSIS

When faced with conflicting moral views, we need some means of assessing them. One proposed framework is 'A Middle Way Model'.² It contains five core elements for analysis: context, persons in relationship, responsibilities, principles of justice and appropriateness.

Context

The context of any case includes the background, settings, cultures, underlying frameworks and ideologies and the persons involved. These aspects of any context help us to understand more fully the perspectives of different persons, their decisions and actions.

In the Child B case, Jaymee's medical background was significant as she previously had been treated for leukaemia. This situation may have affected the likely success of further treatment. Part of her parents' insistence on obtaining aggressive treatment could have related to the expectations within Western culture regarding the existence and use of medical technology. Jaymee's parents may have adhered to a technological imperative, that because the technology existed it should be used.

Any case not only has a background, but takes place within particular settings. The public and private hospital settings produced differing views on whether to treat Jaymee aggressively. The latter was willing to treat her as long as the funds were provided, while the former claimed it was not in her best interests. Interestingly within the legal setting, the health authority not only appealed to Jaymee's best interests, but additionally to its use of resources for her over and against other patients. The courts disagreed with each other about the validity of the health authority's decisions and justifications, but neither *required* it to fund the treatment.

On a different level, the underlying frameworks and ideologies in any case affect the decisions made and justifications given. Frameworks provide the structure and form for moral views, while ideologies provide the content. Two key moral bases highlighted in this case include best interests and utility. Yet, the health authority and Jaymee's parents held different assessments of best interests and utility. Thus, neither moral base necessarily provides a consistent means of reaching a decision in this case. One alternative in attempting to reach a consistent decision and give Jaymee, as patient, the highest priority might have involved seeking to maintain her dignity and integrity as a person. Although the health authority did not appeal to such a holistic view of persons when justifying its decisions and actions in court, the doctors and nurses involved may have given weight to this view when dealing with Jaymee as a person.

The persons involved were affected by the roles and relationships they had with Jaymee and one another. The decisions and justifications they provided, particularly in court, reflected this interaction. As persons and their relationships play a key role in any decision, they require further analysis.

Persons in Relationship

Investigation of persons in relationship involves examining rationality, intrinsic worth and value, the importance of holding a holistic view of persons and the role of community.

Rationality is one important aspect of persons. One role of reason is to provide justification for our decisions and actions. The expectation of and requirement for justification signify that we are accountable to others.³ In the Child B case, all the parties involved had to provide the courts with justifications for their actions. To judge reasons and justifications as being acceptable or unacceptable we must have some standard. The courts provide minimum standards for society, while there also are maximum standards in society. The latter involve surpassing the minimum of protecting people from harm and helping people not only to survive, but also flourish. A biblical example which demonstrates this difference between the minimum and maximum standards is the parable of the good Samaritan. While the priest and the Levite failed to fulfil even a minimum standard, the Samaritan not only stopped to help the injured Jewish man off the road, but provided him with all he needed to recover fully (Luke 10: 29-37).

Valuing and respecting other people can be linked to the intrinsic worth and value human beings have. Valuing Jaymee would not necessarily mean striving to keep her alive at all costs. It might have meant allowing her to die with dignity. Within health care, value and worth is not only attributed to patients, but also to clinicians. In the Child B case this meant the doctors and nurses could not be required to treat Jaymee against their clinical judgment, thus compromising their dignity and integrity both as professionals and persons.

Respecting the dignity and integrity of individuals is part of a holistic notion of persons, viewing persons as multi-dimensional beings, with physical, rational, emotional and spiritual aspects. Acknowledging the physical and emotional effects that further treatment would have on Jaymee,⁴ the doctors and nurses treated her in a more holistic, rather than reductionistic, way.

On a more fundamental level, inter-personal interactions take place within some form of relationship and community. These may be personal or professional. Different relationships and communities affect our decisions and actions. Jaymee's family held a very personal view of her best interests, while the health authority and its clinicians held a broader view of what such treatment would entail for both Jaymee and the wider community. This led to conflict of perspectives and responsibilities which was not easily resolved, even in the courts.

Responsibilities

There are different levels of responsibility. Minimum responsibilities focus on restraining harm and protecting people, while maximum responsibilities aim to do good and help people flourish. These responsibilities also can be expressed as non-maleficence and beneficence.

Jaymee was responsible to communicate her condition and wishes to the doctors and nurses. The clinicians had a minimum responsibility of non-maleficence to her, as well as protecting her best interests and providing care. They did not have a responsibility to provide treatment for her because of pressure from the family. Clinicians also had to consider their responsibilities to other patients. When weighing up the choices in this case, the doctors and nurses involved may have had to choose between the lesser of two harms, that caused by aggressive treatment versus the cancer progression, rather than choosing between a harm and a benefit, namely total cure. In recommending palliative care, they sought to minimise harm to Jaymee and do good.

Jaymee's parents had a responsibility to protect, care for and seek Jaymee's best interests. As she was their child, it seems appropriate that they pressured clinicians for further treatment. Her parents sought the potential benefit of cure rather than to minimise harm to Jaymee. Thus, they may have focused on quantity over quality of life. In sifting through and assessing different levels of responsibility, particularly minimum standards, it is useful to examine principles of justice.

Principles of Justice

There are three key principles of justice: fairness, equality and equity. Fairness to Jaymee may have entailed what she deserved or to what she was entitled. As an ill child, she may not have contributed greatly to society. Therefore, some may have argued she did not 'deserve' expensive treatment. Having already received treatment for leukaemia, she may not have been entitled to further funding. Fairness also entails considering the wishes of Jaymee and her parents and the judgment of the doctors and nurses as to her best interests. In assessing what was fair, the health authority might have considered whether their decision to provide palliative care and not aggressive treatment was universalisable.

Justice as equality requires that similar cases are treated similarly. It provides a level of consistency in moral decision-making and guards against unequal treatment and inappropriate discrimination. One difficulty in this case was the 'extraordinary' or 'experimental' nature of the proposed second bone marrow transplant. These types of treatment offer little in the way of standard guidelines for procedure.

Therefore, it is difficult to assess equality in relation to them.

In contrast to equality, justice as equity allows for justified differences in treatment. These must be based on morally appropriate reasons.⁵ One justifiable reason to support further treatment was Jaymee's age. Justifiable reasons against treatment included its experimental nature, small chance of success and the pain and distress it would cause her. The Appeal Court recognised the difficulties in assessing this case, but upheld the health authority's decision and justifications as appropriate.

Appropriateness

There were differing views of what was appropriate for Jaymee, which were largely affected by the different roles and relationships with her. A key factor in assessing appropriateness was the experimental nature of the proposed second bone marrow transplant. The courts disagreed on whether it was appropriate and should be provided or not. Most doctors disagreed about whether it was in Jaymee's best interests, while one doctor was willing to administer it. The parents viewed it as appropriate to pursue every chance of life. However, their view and actions may be understandable, given Jaymee was their daughter and they did not want her to die, but not judged as appropriate, given the experimental nature of the treatment.

CONCLUSION

In analysing the context, persons and their relationships, minimum and maximum responsibilities, principles of justice and appropriateness, a middle way model highlights a potential way forward, which was not explored or articulated fully in this case. In justifying its decision not to provide further aggressive treatment for Jaymee, but offering palliative care, the health authority need not have appealed to its use of resources. It could have made the same decision on the basis of allowing Jaymee to die with dignity and integrity. From a Christian perspective, this decision and justification would have shown respect for Jaymee's value, worth, dignity and integrity as a human being made in God's image.

Furthermore, this decision *and* justification would have facilitated treating Jaymee as a person and patient in her own right, rather than treating her in relation to other needs. The reality is that human health care needs are endless. They cannot all be met. As stewards of God's creation, this decision also would have exhibited a careful and responsible use of limited resources. This more appropriate choice and justification is highlighted by a middle way model.

A middle way model consists of the five elements of context, persons in relationship, responsibilities,

principles of justice and appropriateness, which provide a framework for approaching and analysing any case. These elements are drawn from themes found in different theories of care⁶ and justice.⁷ The model aims to create an amalgam of themes from care and justice which strikes a balance between specific contexts, persons and relationships and more abstract principles, such as justice as fairness, equality or equity.⁸ Although the model is not without its weaknesses, it provides a more sufficient approach to moral decision-making than either care or justice alone. Its ultimate success will be tested in the practice of health care decision-making.

Throughout the Bible, we can see that God is concerned with people and relationships. God valued people enough to send his only son, Jesus Christ, to die for us. Jesus deals with people in ways which clearly exhibit care and justice. His interaction with people restores dignity and integrity to the down-trodden and calls the selfish and proud to account. The example of Christ blends care, justice and appropriateness to each individual with whom he has contact. The challenge for us is to balance these in the context of our human community.

REFERENCES

- ¹ R v Cambridge Health Authority, ex p B [1995] 2 All ER 129. Bradbury, Richard, Vikki A. Entwistle, Lesley J. Pehl and Ian D. Watt. 'Media Coverage of the Child B Case.' *British Medical Journal* 312 (1996): 1587-91. New, Bill. 'The Rationing Agenda in the NHS,' *British Medical Journal* 312 (1996): 1593-1601.
- ² Wasson, Katherine. 'The Ethics of Care or the Ethics of Justice?: A Middle Way Model.' PhD diss., The Whitefield Institute and the Open University, 1998.
- ³ Cook, E. David. 'The Use of Rationality in Religious and Metaphysical Argument.' PhD diss., University of Edinburgh, 1973.
- ⁴ R v Cambridge Health Authority ex p B [1995] judgment, All ER 129.
- ⁵ Downie, Robin S. and Elizabeth Telfer. *Caring and Curing: A Philosophy of Medicine and Social Work*. New York and London: Methuen, 1980, 76-7.
- ⁶ Noddings, Nel. *Caring: A Feminine Approach to Ethics and Moral Education*. Berkeley and Los Angeles: University of California Press, 1984. Benner, Patricia E. and Judith Wrubel. *The Primacy of Caring: Stress and Coping in Health and Illness*. Menlo Park and Wokingham: Addison-Wesley, 1989. Blustein, Jeffrey. *Care and Commitment: Taking the Personal Point of View*. New York: Oxford University Press, 1991. Downie and Telfer, *Caring and Curing*.
- ⁷ Rawls, John. *A Theory of Justice*. Cambridge: Belknap Press of Harvard University Press, 1971. MacIntyre, Alasdair. *After Virtue: A Study in Moral Theory*, 2nd ed.. Notre Dame: University of Notre Dame Press, 1984. MacIntyre, Alasdair. *Whose Justice? Which Rationality?* Notre Dame: University of Notre Dame Press, 1988.
- ⁸ Gilligan, Carol. *In a Different Voice: Psychological Theory and Women's Development*. Cambridge: Harvard University Press, 1982. Gilligan refers to the former approach to moral decision-making as the ethics of care and the latter as the ethics of justice.

For Further Reading

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| J.F. Kilner | <i>Who Lives? Who Dies?</i> | New Haven: Yale University Press, 1990 |
| BMA | <i>Rights and Responsibilities of Doctors</i> 2nd ed. | London: BMJ Publishing, 1992 |
| David Cook | <i>Patient's Choice</i> | London: Spire, 1993 |
| David Cook | <i>The Moral Maze</i> | London: SPCK, 1983 |

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