Conjoined Twins Contextualised Scenario

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Learning Outcomes

The primary objective of the Scenario is to provide the background of a real-life case that will enable the students to apply a basic knowledge and understanding of moral theories and ethical principles to the resolution of a range of complex moral dilemmas that can occur in practice.

- The students are given an opportunity to consolidate an appreciation of, not only how these theories and principles can be useful in practice, but also of how the different perspectives, values and responsibilities of interested parties need to be carefully considered and weighed in order to reach a decision about the final course of action.
- Students learn to:
  - understand the nature of a 'moral dilemma'
  - identify the issues raised by a real-life case and to construct moral arguments by application of ethical theories and moral principles,
  - communicate ethical arguments effectively to an audience,
  - develop their powers of critical reasoning and to defend different positions,
  - reflect upon and justify their own moral values by listening to opposing viewpoints.
- Students gain experience of:
  - independent research for preparation of presentations
  - accessing sources of information (mainly media articles) from the Internet

Assessment of Learning Outcomes

Learning outcomes of this Scenario can be assessed by a number of different means:

- Determination of whether ethical learning outcomes have been met can be achieved by the teacher's own evaluation of the extent to which the students have contributed to the session by freely engaging in discussion and debate of the issues from both informed and also personal standpoints.
- Feedback, either informally or by questionnaires, from the students as to the levels of stimulation, learning, interest and satisfaction and any suggestions for modification or improvement is also useful.
Other methods, such as self- or peer-assessment or evaluation of presentations, in creating a more formal atmosphere, can sometimes reduce the effectiveness of such a session that relies upon the confidence of each student to contribute and to express personal feelings within a relaxed and non-judgmental environment.

However, should a more formal assessment be required, then this session would lend itself to teacher evaluation of the presentation skills, material delivered and response to questions for each student. In this case, peer assessment by ranking individual presentations in order of merit would also be appropriate.

Teaching Structure/Format

This Scenario has been offered to Level 2 Undergraduates on Health Science and Human Biology degrees as part of a module entitled "Introduction to Health Care Ethics". Only a small minority have experience of working in a professional environment.

It is normally presented within a 2-hour seminar session to a maximum 10 students with each student taking on a separate role. However, it could be equally well presented to larger groups with students working in pairs.

The teacher in performing the role of a facilitator needs to have knowledge of moral philosophy and be familiar with application of ethical theories and moral principles to decision-making in health care practice. A familiarity with and understanding of relevant law (listed in last section: Relevant Codes/Legislation) would also be advantageous. It would be appropriate for a postgraduate with the requisite knowledge and experience in leading group discussion to take on this role.

Accommodation should provide an informal environment for group discussion and OHP and/or PowerPoint for student presentations.

Students are allocated the following roles:

- Mary
- Jodie
- the parents
- a lawyer representing the parents
- a Roman Catholic priest
- a lead surgeon involved in the operation
- a Consequentialist - an action is moral if 'the end justifies the means'
- a Deontologist - an action is moral so long as moral rules are followed without exception
- a ProLife Alliance representative
- a presiding judge of the Court of Appeal - the decision

Each student is given an outline of the case and guidance on the underlying ethical issues at least a week in advance of the seminar session and is asked to prepare a 5-minute presentation, outlining and critiquing the main moral and legal arguments relating to the surgical separation of the twins from that particular individual's perspective. Students should be encouraged to do further research of their own by accessing books, media and journal articles and internet source material that provide more detailed information about the case and how the debate evolved (Examples of reference sources are given at the end of the case outline). After each presentation, time is allowed for group discussion.

Finally the students are given an opportunity to express and justify their own views and to agree or disagree with the final decision to proceed with the separation and to reach an overall group decision. It can also be interesting to ask students if the session has caused them to change their own original positions.

Time permitting, an extension of discussion could consider the more recent separation in July 2003 of 29
year-old conjoined twins, Laleh and Ladan Bijani, and compare and contrast the ethical issues of this case. Issues for consideration would include: adult consent, questionable degree of autonomy for each twin, acceptance of high degree of risk v. psychological suffering of remaining conjoined, non-life threatening condition, best interests and the possibility of successful separation resulting in independent lives for both twins, the surgeons’ duty to do no harm v. the wishes of the twins to be separated.

Approach

- It is advisable for the teacher to provide guidance to the students before they prepare their presentations on:
  - How they might apply their knowledge of ethical theories and principles to the case,
  - How to decide upon the relative importance of different theories and principles in resolving moral dilemmas by critical analysis and evaluation of the strengths/weaknesses of ethical arguments. This could be achieved by working through another example of another case with the class.
- Each student will need to empathise with the individual whose role they are playing. However, they should be aware of a common view amongst moral philosophers that arguments based on emotions, prejudices or intuitions, although often seemingly persuasive, lack a rational basis and are therefore considered to be less relevant than, and are superseded by, reasoned ethical arguments in resolving moral dilemmas. For this reason, students are also discouraged from discussing personal feelings. However, disclosure of personal experiences that have a direct bearing on discussion of the case should be allowed provided that such confidences are respected within the class. The class needs to be made aware of requirements for protection of confidentiality before the session.
- The case contains material of sensitivity, particularly for Roman Catholics and those of other religions that hold similar views on the sanctity of human life, right to life and respect for God's will. Teachers might, therefore, need to consider the appropriateness of this Scenario for particular classes.

The Scenario

On 8 August 2000 conjoined twins, known as Mary and Jodie, were born at St. Mary's Hospital, Manchester.

An ultrasound scan at three months into the pregnancy had revealed that the foetuses were conjoined. The parents lived on the island of Gozo, off Malta, in a strongly Roman Catholic community where abortion is widely condemned as evil and where medical facilities are inadequate, they travelled to Britain for specialist care. At this stage the parents were apprehensive but hopeful of a successful outcome.

The reality of the health status of the twins was revealed at their birth. Their bodies were fused at the base of their spines and so had the appearance of a continuous trunk with legs splayed sideways. Additionally there was fusion of circulatory systems and the twins shared a single bladder. Mary, the weaker twin, had no effective heart, her lungs had never inflated and she had only a primitive brain. She was using Jodie as a life support machine and was growing at her expense. Jodie was thought to have normal brain function.

Surgery to separate the twins would inevitably result in Mary's death but without being divided, the strain on Jodie's heart would kill both twins at between 3 and 6 months old. Surgery was Jodie's only chance of survival.

The medical team were of the opinion that surgery to separate the twins should go ahead. The parents refused to give consent for the operation on grounds of devout religious convictions that their children's future should be entrusted to God's will and that nature should take its course even if it meant that both twins would die. They claimed to love their daughters equally and believed that each had an equal right to life. They could not contemplate choosing to save the life of one at the expense of the other's death. Additionally, it was likely that Jodie would need specialist
care following surgery and could be left with serious long-term handicaps following surgery and they could not envisage returning home without her. The hospital applied to the Family Division of the High Court for a Court Order giving permission for surgery.

On August 25, the judge ruled in favour of the medical team and gave permission for the operation to go ahead. Although he considered seriously the feelings and rights of the parents, he finally overrode their decision in favour of medical evidence that both twins, unless separated, would die and it not being in Mary's interests to live.

This judgment was badly received not only by the parents but also by the media and public opinion was divided. There were comments that the decision was legally and ethically insecure in that it supported the idea that doctors could turn to the support of the Courts when they failed to reach agreement with parents; could set a precedent for babies lives being sacrificed to save others; and undermined respect for parental rights and concerns.

By mid September, although Mary was getting bigger, Jodie was found to have stopped growing normally. The ProLife Alliance came forward at this time with an offer of care, negotiated with the Vatican, for the twins at a hospice in Italy. The parents, however, were in a no-win situation. Should they try to return home or to Italy with the twins then the law could intervene by making the children wards of court in the interests of their welfare thus prohibiting their being taken outside the country. The parents took their case to the Court of Appeal.

The Appeal Court Judges deliberated long and hard on issues raised by the case. Are there justifiable grounds for disregarding the parents' right to decide for their children? Can killing ever be lawful? Could parents consent to or the law condone such an act? Does Mary have an interest in her existence? Should her life be viewed as futile? Is Mary merely a "creature" in the eyes of the law? Might it be God's will that Mary die since she was not born with the capacity to live? On 22 September, the Court of Appeal upheld the earlier High Court decision. The majority of medical opinion supported the judgment. The Roman Catholic Church condemned it. The parents still had the option of taking the case to the House of Lords and ultimately the European Court of Human Rights but did not take it up and reportedly became reconciled to the operation. On 3 November, legal moves by lawyers for the ProLife Alliance failed to remove the Official Solicitor, Mary's guardian, in a last-minute attempt to take case to House of Lords.

The 20-hour operation to separate Jodie and Mary took place on 6 November, amidst worldwide media attention, just before the twins were 3 months old. Mary died during the surgery despite doctors' efforts to revive her. Jodie survived, though still needing extensive reconstruction surgery and skin grafts over a number of years. She is now approaching her third birthday. She is walking, has normal brain function and is expected to have an average life span.

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**Useful sources of further information:**

- BBC News, 22 September 2000:
  - Siamese twins: The reaction
  - Judge: An excruciating decision
  - Ethics expert: Twin decision wrong
  - Siamese twins: A surgeon's view
  - Siamese twins: The judgment


Nicholson, R: "Don't take one child's life to save another", The Independent on Sunday, 27 August 2000.


Rogers, I: "Double dilemma - should doctors be allowed to sacrifice one Siamese twin to save the other?", The Sunday Times, Sept. 10, 2000.


Websites:

- [http://www.prolife.org.uk](http://www.prolife.org.uk)
- [http://www.the-times.co.uk/onlinespecials/britain/siamese/](http://www.the-times.co.uk/onlinespecials/britain/siamese/)

Moral Context/Underlying Ethical Issues:

This Scenario allows for the identification of a wide range of ethical issues, and presentation and critical analysis of arguments. The main issues are listed below and placed within a broader context of moral theory and ethical principles related to health care practice. They can be used as a basis for discussion by both teacher and students. This list is not intended to be exhaustive and students should be encouraged to think of additional issues.

**Moral status, sanctity of life, rights and the value of life.**

- Resolution of the dilemma based on reasoning from respect of rights is problematic. Opinion is divided on the moral status of the twins, and therefore consensus as to whether or not Jodie and Mary have rights to life is impossible.

- In this case, the doctrine of the Roman Catholic Church, which holds life to be sacred from conception, the stage at which humans attain full moral status and are conferred with rights, is central to the parent's decision. At the other extreme is the view that full moral status, or personhood, is not attained until some time after birth and therefore, because newborn babies cannot value their lives and have no rights, they cannot by wronged by being killed (Harris, 1985). In between is a spectrum of different views as to the developmental stage at which rights are conferred.

- Dependent on viewpoints there are three possibilities: both twins have equal rights to life; neither twin has a right to life; or Jodie has a right to life but Mary does not.

- If, as the parents believe, the twins have equal rights to life that are owed respect then another right, to bodily integrity, should also be considered. Mary is depriving Jodie of this right.

Respect for the right of parents to make treatment decisions for their children
Parents have a legal and moral right to consent on behalf of their children to medical interventions. This right derives from parental duties to obtain adequate medical care for their children and is exercised in children's best interests. Problems arise when a parental decision is contrary to medical opinion and to the child's welfare.

The difficulty in this case is deciding upon whether the parent's refusal of consent to surgery, based upon their devout religious beliefs, should be respected at the cost of the twin's lives. A parallel situation arises in the case of refusal of Jehovah's Witness parents to life-saving blood transfusions for children and intervention of the Courts to overrule such decisions by implementing the wardship jurisdiction.

Opinion is divided on the appropriateness of involvement of the courts to pass judgement. Should parental rights be upheld at all costs or their beliefs and concerns ignored? Or should medical opinion trump parental rights? Conflicting interests of Jodie and Mary

The law requires that children's interests be held as of paramount importance but is unclear as to how to proceed when there is conflict between the interests of two children.

The ethics of sacrificing an innocent child's life for the benefit of another

According to deontology (rule-based moral theory) people should be treated as ends in themselves and killing is always immoral regardless of the outcome. Therefore as surgery would inevitably result in the death of Mary it is considered to be a wrongful act.

Consequentialist theory (‘the end justifies the means’) regards an act as being moral if it brings about an overall good consequence. In this case, the best outcome is the saving of one life, when it is impossible to save the lives of both. It is questionable, in this case however, whether the saving of one life constitutes sufficient justification for causing the death of another.

Mary is incapable of independent existence and is destined to die with or without the surgery. Jodie, however will die without surgery but, if separated, could live an independent life, albeit with the possibility of some degree of handicap, with normal intelligence and life expectancy.

Does Jodie have a right to be rid of a parasite that is killing her?

There are parallels with the argument for justification of abortion on grounds of the right of self-ownership of one's body and also self-defence when the foetus, and continuation of pregnancy, is posing a threat to the life of the mother (Thomson, 1971).

Mary is assaulting Jodie and is a parasite on her as she is draining her lifeblood. Inadvertently Mary is bringing about her death. Jodie is an unwilling victim and arguably has a right to be free of Mary.
From self-ownership, even though Mary is an innocent intruder, should Jodie have a just prior claim on her body irrespective of whether or not Mary has rights?

Mary's inevitable death on separation can only be justified if there is no possibility of providing the same defence for Jodie by a lesser harm.

**Were the doctors being unduly paternalistic in trying to override the decision of the parents?**

- The argument rests on the balance between paternalism ('doctor knows best') and patient autonomy (freedom to make decisions about medical treatment). Can it ever be justified for medical opinion to override autonomous decisions by patients?
- Assuming that the parents had been adequately informed about and had understood the nature of the operation, its possible outcomes and extent of risks and that their decision to refuse consent for surgery had been made freely, then arguably their decision should have been respected.
- In this case the majority of doctors supported the decision to operate. However, in the absence of parental consent, the surgeons might be liable in law for criminal assault on Mary since they could not perform the operation without unlawful touching of her body.
- Was there conflict between the interests of the doctors and the parents? To what extent might the medical decision have been influenced by professional challenge and media attention?

**The problem of conflict between duties of doctors to their patients.**

- Doctors have duties to do their best, including the preservation of life, for their patients (beneficence) and to do no harm (non-maleficence).
- This case presents a serious dilemma for the doctors. On one hand they have a duty to save the life of Jodie but on the other they also have a duty not to harm Mary. Surgery would inevitably end Mary's life and, by causing her death, the doctors could be found guilty of committing the offence of murder.
- It is not possible to preserve the life of Mary. With or without surgery it is unlikely that her life can be sustained for longer than a few months. Her condition is not compatible with independent existence. The doctors would be failing in their duty to Jodie however if they did not perform the operation. They would be allowing her to die when she could have been saved. Would the doctors be any less morally culpable by allowing Jodie to die through non-surgery than by directly causing her death?
- Is there an ethical distinction between letting die and killing? The relevant doctrine is one of 'acts and omissions', frequently applied to the debate on active and passive euthanasia. This doctrine supports there being a moral difference between a direct act designed to result in the death of a patient and the withholding of treatment that produces the same result (Rachels, 1975). The morality of this doctrine is often disputed.
- In this case, it could be argued that failure to operate, in prolonging Mary's possible pain and suffering and resulting in the death of both twins, carries at least equal moral culpability to deliberately causing the death of Mary. Moreover, it could be argued to be morally worse since both twins would die and the surgeons would have failed to save a life when they could have done so.
- A counterargument would be that a decision not to operate (negative action) might not necessarily result in the death of one or both twins (that they could, against all odds, survive), whereas surgery to separate (positive action) would inevitably result in Mary's death and would therefore be a greater moral wrong.
Is there an ethically significant difference between intentional killing and causing death as an indirect but foreseeable consequence?

- A comparison can be drawn between this case and the administration of diamorphine to terminally ill patients. Doctors can claim that, although they foresee that a particular dosage will be lethal, their primary intent is pain relief.
- Although Mary's death was foreseeable, indeed inevitable, the main intention of the surgery could be argued to be the saving of Jodie's life rather than the killing of Mary.
- The final ruling of the Court of Appeal, in absolving the medical team from performing a criminal act of murder, rested on the argument for there being a ethical, and in this case also legal, distinction between an act (in this case the separation of the blood supply of the twins) intended to bring about Mary’s death so that Jodie could live, and the same act performed primarily to save Jodie's life (by restoring her own blood supply) but foreseeing Mary's death as an indirect consequence.
- But how convincing is this argument? Can intended and foreseeable outcomes be distinguished in a way that matters morally?

Would the decision in favour of separation amount to a state sanctioned murder - one life can be taken to save the life of another?

- This case represented a landmark legal decision. Might the removal of moral and legal restraints on causing death in this case set a precedent for justification of killing, for example, anencephalic newborns without parental consent for harvesting organs to save other babies? (Nicholson, 2000). Is it likely that the decision will be applied more widely and become integrated into practice and policy?
- A similar argument has arisen in relation to the debate on the legalisation of euthanasia and the likelihood of an increase in unethical killings of terminally ill patients unduly pressurised to satisfy relatives' interests or to relieve the burden on society.
- Are slippery slopes inevitable? To what degree can society act to prohibit those practices that it views to be morally unacceptable?

Relevant Professional Codes (if any):

Legislation:

Professional Code:
Hippocratic Oath - Modern version Excerpt: "Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God"