UNCC300 CASE STUDY 2:
HUMAN DIGNITY AND SAVIOUR SIBLINGS

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CASE STUDY: HUMAN DIGNITY AND SAVIOUR SIBLINGS

INTRODUCTION

Recent advances in genetics can now be used to conceive a child who is a direct tissue match for an existing sibling suffering from a life-threatening illness. The child born as a result of this process is called a saviour sibling as he or she has the capacity to save the life of the existing sibling through donation of organs or other tissue.

The first such case of a child being specifically ‘created’ to save a sibling’s life was the case of Molly Nash. Molly was born with a rare genetic disease which required an exact stem cell match to enable her to survive. Molly’s parents employed the use of reproductive technology to ensure a direct match in their next child. Watch this video, ‘Saviour Sibling or Spare Part Baby’ (or read the transcript) produced by a group of medical students, which introduces us to the ethical questions surrounding the birth of Molly’s brother, Adam.

The Molly Nash case sparked controversy and debate which was picked up in the media. These reports from the BBC and CBS News are among the many media treatments of this case.

Although the number of cases of therapeutic reproduction is small, the stakes are extremely high for the families directly involved and for the community which must decide what it will permit to be done to children who, by virtue of their age, cannot express their own perspective. In some countries, such procedures are illegal, and special permission must be sought in order to allow them to be carried out, as this case in England shows. A similar situation arose more recently in Victoria.

The creation of saviour siblings raises significant questions for bioethics, medicine and legal regulation. In order to produce exact matches preimplantation genetic diagnosis (PGD) is necessary. This means that embryos are created using IVF techniques and then tested. If these human embryos are found not to be the required match, they are discarded. This is a source of much controversy. Such use of human embryos raises questions of personhood and human dignity. It also raises questions of the eventual uses of this technology. Is it equally acceptable to select embryos for other traits like eye colour or gender? One response to this controversy has been articulated in this way:

Certain attempts to influence chromosomal or genetic inheritance are not therapeutic but are aimed at producing human beings selected according to sex or other predetermined qualities. These manipulations are contrary to the personal dignity of the human being and his or her integrity and identity. Therefore in no way can they be justified on the grounds of possible beneficial consequences for future humanity. Every person must be respected for himself: in this consists the dignity and right of every human being from his or her beginning.

In reality, saviour siblings can be called upon to undergo other significant treatment in order to assist their sibling. Not only are they bred to save a sibling but the necessary medical treatment can be invasive and uncomfortable for the saviour sibling. In some cases tissue (e.g. bone marrow) or organ transplantation are required.

Does this mean that the saviour sibling is being treated as a commodity?

What implications does this have for the autonomy and human dignity of the donor?

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THREE MAIN PERSPECTIVES

Perspective 1: Therapeutic reproductive technology upholds human dignity only in so far as it allows for the autonomous decision making of both the saviour sibling and their ill sibling.

Perspective 2: Therapeutic reproductive technology enhances human dignity because it is undertaken to preserve human life and allow flourishing.

Perspective 3: Therapeutic reproductive technology undermines the inherent dignity of the human person because it relies on scientific selection of embryos and commodifies the human person.

As you read the articles in the links below, analyse the understanding of human dignity that underpins the arguments and consider how this understanding of human dignity is being brought to bear on the question of saviour siblings. Note that you may find two authors of different ethical positions explaining dignity in a similar way or in more than one way such that it could fit into the same quadrant as another author or into several quadrants. Look carefully for the nuances and underlying assumptions that further qualify the understandings of human dignity such that the authors nonetheless arrive at different ethical positions.

In some of the articles provided, the authors also refer to other authors who offer perspectives on dignity different from their own in relation to the question of saviour siblings. You may wish to use the references in the articles provided to trace these additional perspectives.
The first reading provides a comprehensive overview of therapeutic reproduction. It also comments on the different ways that bioethicists have approached how we regulate the creation of saviour siblings. As you read it, think in particular about what difference, if any, the age of the recipient child or donor child makes to questions of human dignity. Do we regard children as having ‘autonomy’ to decide what medical procedures they should undergo? Is this the parent’s choice alone? What does this mean for human dignity? Does the way we treat children mean that human dignity is something you develop with age or is it present at all times?


One response to specific controversies in ethics, bioethics and questions of human dignity is found in literature. The questions about what it means to be human and what the basis of human dignity is a central issue when we think about the creation of saviour siblings through therapeutic reproduction: for the saviour sibling is it something like the first approach to human dignity which is always present or is it something that can be acquired (or lost)? These questions are reflected in literature which has long been a part of what bioethicists use as tools for analysis. 4 Richard Storrow deals with the questions of human dignity and therapeutic reproduction in this journal article which engages with Kazuo Isiguro’s novel, Never Let me Go as well as another significant novel in the area, My Sister’s Keeper, by Jodi Picoult.


The following podcast from Globalising European Bioethics Education, a European Union-funded project, gives an overview of the technology and bioethical questions by exploring the story of the Nash family and the different standards of regulation of PGD in different countries across the world. This difference in regulation raises its own ethical questions.

Globalising European Bioethics Education (GLUEBE), "Saviour Siblings Episode 2," in This Is European Bioethics. Read this transcript of the podcast (the podcast has been discontinued, but the transcript is still available).

Finally, we have provided references to additional articles for you to find yourself, bearing in mind that being able to locate relevant information goes towards meeting the requirements of Graduate Attribute 8. You should access these resources if you choose this case study for your final assessment.


