OBM Genetics



Book Review

Case Studies in the Ethics of Assisted Reproduction, by Louise P. King & Isabelle C. Band, Switzerland: Springer Cham, 152 Pages, Ebook, 978-3-031-41215-8

Donny Japly Pugesehan⁺, Vernando Yanry Lameky⁺, Agustinus Mathinus Luther Batlajery^{+,*}

Universitas Kristen Indonesia Maluku, Jln Ot Pattimaipauw, Kota Ambon, Maluku, Indonesia; E-Mails: <u>pugesehan_d@yahoo.com</u>; <u>vernandoyanrylameky@gmail.com</u>; <u>agustinus.m.l.batlajery@ukim.ac.id</u>

- + These authors contributed equally to this work.
- * **Correspondence:** Agustinus Mathinus Luther Batlajery; E-Mail: <u>agustinus.m.l.batlajery@ukim.ac.id</u>

Academic Editor: Thomas Liehr

OBM Genetics	Received: June 12, 2024
2024, volume 8, issue 3	Accepted: August 15, 2024
doi:10.21926/obm.genet.2403258	Published: August 21, 2024

Abstract

"Case Studies in the Ethics of Assisted Reproduction" explores the moral and ethical implications of assisted reproductive technologies (ART), such as in vitro fertilization (IVF), surrogacy, and genetic screening. These findings outline ethical dilemmas, including the importance of informed consent, and highlight a multidisciplinary approach involving law, bioethics, reproductive endocrinology, and reproductive biology. Using case studies, the findings address ethical challenges in ART practice, such as the transfer of embryos affected by genetic diseases, non-medical sex selection, and the provision of fertility services to patients with medical comorbidities. The findings also emphasize the importance of education and training for new practitioners and the development of ethical guidelines for new technologies such as germline gene editing and same-sex reproduction. The main findings of this book include three essential aspects. 1) There is an urgent need for comprehensive and detailed ethical guidelines to ensure that every action conforms to high moral standards. 2) Transparent informed consent is essential so the patient truly understands and agrees to the



© 2024 by the author. This is an open access article distributed under the conditions of the <u>Creative Commons by Attribution License</u>, which permits unrestricted use, distribution, and reproduction in any medium or format, provided the original work is correctly cited.

procedure. 3) Before implementing a new technology in clinical practice, the risks and benefits must be thoroughly evaluated to ensure patient safety and effectiveness. The main conclusions indicate that ethical considerations must always be in line with the latest technological developments in the field of ART to ensure responsible and ethical practice. These findings are a valuable resource for educational institutions, health professionals, law and ethics scholars, policymakers, and the general public interested in the ethical complexities of assisted reproduction.

Keywords

Ethics of assisted reproduction; in vitro fertilization (IVF); explanation and approval; education and training; multidisciplinary approach

1. Introduction

"Case Studies in the Ethics of Assisted Reproduction" is a field of study that investigates the moral and ethical implications surrounding assisted reproductive technologies (ART), such as in vitro fertilization (IVF), surrogacy, genetic screening, and other methods designed to help individuals or couples in have children [1-4]. This case study explores various ethical dilemmas, starting with informed consent and ensuring patients fully understand the risks, benefits, and alternatives to ART procedures [5, 6]. King & Band (2023) [7] explores this in their book Case Studies in the Ethics of Assisted Reproduction.

In applying ethics in assisted reproduction, various innovative techniques and steps can be taken to ensure this practice is carried out responsibly and by the ethical principles in this book. One crucial approach highlighted by the authors is multidisciplinary, bringing together views from law, bioethics, reproductive endocrinology, and reproductive biology to provide comprehensive ethical guidance. This collaborative team of experts integrates different perspectives to address complex ethical issues. Additionally, education and training for new practitioners is essential, with programs focusing on ethical principles and guidelines in assisted reproductive technology (ART). Developing a curriculum that includes case studies, ethical principles, and practical scenarios is also essential for professional training.

Structured ethical guidelines, including the development of clear and detailed codes of ethics as well as specific guidelines for new technologies such as genetic editing and same-sex reproduction, are urgently needed. The role of law in the development of structured ethical guidelines is essential to ensure that medical practices and new technologies comply with established standards. The law serves as a framework governing the creation and implementation of clear and detailed codes of ethics, covering various aspects of new technologies such as genetic editing and same-sex reproduction. In this context, law helps establish boundaries and rules and provides monitoring and enforcement mechanisms to ensure compliance with these ethical guidelines.

Proactively considering new technologies is also essential in reviewing and developing ethical guidelines as technologies such as in vitro-derived gametes and germline editing advance. Before implementing a new technology in clinical practice, an in-depth evaluation of the risks and benefits should also be performed. In addition, patient-specific considerations, such as developing ethical

guidelines addressing fertility issues in elderly patients and oocyte and embryo donation, should be created. Transparency and informed consent are also essential aspects, where patients receive complete and transparent information regarding procedures, risks, and benefits and prepare informed consent documents that are easy for patients from various backgrounds to understand. Continuous evaluation and research through case studies and research are also needed to evaluate the application of ethics in ART practice. The authors of this book emphasize the importance of a multidisciplinary and collaborative approach to addressing ethical challenges in assisted reproductive technologies.

The book is novel in several ways. 1) it uses a multidisciplinary approach to provide comprehensive ethical guidance. The book collects essays from various experts, including law scholars, bioethics, reproductive endocrinology, and reproductive biology, ensuring that all relevant perspectives are considered. 2) It highlights the importance of education and training for new practitioners in assisted reproductive technology (ART). With a focus on mastering ethical principles and guidelines, this book offers an educational program designed to address complex ethical issues that frequently arise, such as providing fertility services to elderly patients and the ethical considerations surrounding oocyte and embryo donation. 3) The book proactively responds to technological advances in ART by developing ethical guidelines for new technologies such as in vitro-derived gametes, same-sex reproduction, and germline editing. This approach ensures that ethical considerations always align with the latest technological developments in the field. 4) emphasize transparency and informed consent by providing precise and complete guidance to patients regarding assisted reproductive technology's procedures, risks, and benefits. This book also develops an informed consent document that is easy for patients from various backgrounds to understand.

2. Overview of the Content

This book provides a comprehensive insight into the Ethics of Assisted Reproduction, which consists of two parts (10 chapters) with clear, concise explanations and accompanied by examples or case study results that strengthen ideas or points of view. Chapter 1 provides a comprehensive overview of the principles and frameworks guiding ethical decision-making and reproductive medicine policy development. This chapter emphasizes the importance of not applying a single ethical model or framework because different models can produce different results. Additionally, it serves as a reference for understanding the complex ethical dimensions of moral dilemmas in reproductive ethics, highlighting the importance of considering various ethical theories and principles such as principle, utilitarianism, and moral status, as well as other essential aspects such as informed consent.

Chapter 2 concludes that the legal landscape in the United States regarding Assisted Reproductive Technology (ART) is fragmented and inconsistent. This chapter highlights the uncertainty of constitutional protections for ART, especially in the wake of the US Supreme Court decision ending constitutional protections for abortion rights. Federal legislative efforts in this area have been minimal, with the primary focus being on prohibiting government funding for research involving human embryos, thereby impeding progress in areas such as germline genome editing and mitochondrial replacement therapy. Most regulation occurs at the state level, resulting in a wide variety of laws regarding such topics as parental status, surrogate parenting arrangements, and

embryo sharing after divorce. The chapter also notes that new reproductive technologies may struggle to gain strong support due to lacking a comprehensive national regulatory framework.

Additionally, more controversial ART techniques and practices, such as germline genome editing and mitochondrial replacement therapy, raise significant ethical and legal dilemmas. Germline genome editing, for example, is raising concerns about the long-term implications and potential misuse of this technology, while mitochondrial replacement therapy is fueling debate about interventions at the cellular level that can be passed on to the next generation. The need for more clarity in laws and regulations and the diversity of public views on these issues further exacerbates this controversy. Thus, the development of ART in the United States faces complex legal, ethical, and regulatory challenges.

Chapter 3 discusses the ethical complexities surrounding the transfer of embryos affected by genetic diseases. This chapter highlights some vital ethical dilemmas, such as how to manage a situation where the only chance of having a genetically related child is through the transfer of affected embryos, as well as considering the autonomy of physicians and the welfare of the resulting children. Disease severity is an essential factor in decision-making, as in the case of cystic fibrosis, which has a broad phenotypic spectrum and future treatment expectations. Doctors often must balance a patient's procreative freedom with their professional conscience, and according to the Ethics Committee of the American Society for Reproductive Medicine (ASRM), it is ethically acceptable for providers to deny requests to transfer embryos for life-threatening conditions that cause severe and premature debilitation. Additionally, this chapter discusses cases in which parents intentionally create and transfer diseased embryos, such as same-sex couples hoping to integrate a deaf child into Deaf culture. The argument that the birth of children with diseases or defects is detrimental to society is considered problematic, as screening for embryos with conditions such as Down Syndrome can reduce acceptance of individuals living with such conditions and make them feel undervalued. The reproductive freedom of parents in determining the parameters of the desired child is also acknowledged; however, physicians who are uncomfortable with the transfer of affected embryos should discuss this with the patient before treatment begins. The child's welfare is a significant concern, especially if the disease is confirmed, as in the case of cystic fibrosis. This chapter also emphasizes the importance of considering various ethical aspects in decisions regarding the transfer of embryos affected by genetic diseases, including the welfare of the child, the autonomy of the doctor, and the social impact of the decision.

Chapter 4 discusses ethical considerations and decision-making processes in the selection for transfer of aneuploid or mosaic embryos. Patients have the right to request the transfer of the embryos after obtaining full consent, but doctors can refuse if they believe the procedure could cause severe defects or illnesses. The ethical principles used as guidelines include reproductive autonomy, doctor autonomy, professional conscience, nonmaleficence, procreative beneficence, and child welfare. Informed consent from genetic counselors and mental health providers ensures patients understand potential outcomes and risks. The development of clear guidelines regarding the conditions for embryo transfer is necessary and must involve genetic counselors. This chapter also outlines the complexities of mosaic embryo transfer and provides examples of situations in which a couple may request the transfer of an abnormal embryo for various reasons.

Chapter 5 discusses ethical considerations and implications of sex selection for non-medical reasons. This chapter explores related ethical debates, including concerns about the reinforcement of gender stereotypes and the distortion of sex ratios. Proponents argue that nonmedical sex

selection can improve parent-child relationships by fulfilling parents' wishes and reducing the burden on unwanted children because of their gender. However, there are concerns that this could lead to social instability, increased prostitution, human trafficking, and violence, especially in countries with solid gender preferences. The risk of sex ratio distortion is more relevant in countries like India and less significant in the US. A committee of the ASRM has not taken a firm stance on the ethics of nonmedical sex selection but is encouraging clinics to develop their policies. The "do not harm" principle highlights that sex selection with stereotypical gender role expectations can hurt a child's well-being. Further research is needed to assess the potential harm of this practice.

Chapter 6 discusses ethical considerations related to providing fertility services to patients with medical comorbidities. Patients with this condition have a higher risk of experiencing peripartum complications that can endanger their health and that of the unborn baby. Although reproductive autonomy is essential, healthcare providers must ensure the well-being of patients, which may require restrictions on freedom to prevent harm. A reproductive endocrinologist should consult with a maternal-fetal disease specialist to ensure treatment decisions are based on thoughtful consideration. Pregnancy remains a reasonable option for many patients with proper monitoring. Doctors should provide clear and informative advice to patients undergoing or considering fertility treatment. Patients, both individuals and couples seeking help to achieve pregnancy, need to receive full support in this process. Apart from that, no party, doctors, other medical personnel, family, partners, or external parties, such as the government, can pressure patients to continue the pregnancy. Patients should feel free to make decisions based on the information they receive and their circumstances without pressure from anyone. Decisions made independently and without pressure will ensure that patients can undergo treatment with peace of mind and according to their wishes and conditions.

Chapter 7 discusses ethical considerations and implications of preimplantation genetic testing for conditions emerging in adulthood. Preimplantation genetic testing for monogenic defects may be ethically justified if the condition is severe and there is no effective intervention. Children born with genetic conditions such as BRCA may lose autonomy in decision-making, raising ethical concerns about when and how to discuss the diagnosis. Parents should understand the potential impact on the child's future independence when deciding about preimplantation or prenatal testing. The risk of misdiagnosis due to Allele Dropout (ADO) has been minimized with the latest PGT-M technique, increasing the reliability of the test. However, access to these services remains an issue, raising concerns about fairness and equality. These conclusions highlight the ethical complexity and need for careful decision-making and counseling in preimplantation genetic testing for adult conditions.

Chapter 8 discusses ethical considerations related to providing fertility services to patients of advanced reproductive age. The use of assisted reproductive technology (ART) continues to increase in the United States, including oocyte and embryo donation. Patients of advanced reproductive age require a higher level of care due to increased peripartum risks, so they are advised to undergo comprehensive medical testing that focuses on cardiovascular and metabolic fitness. Reproductive endocrinologists should consult maternal-fetal medicine specialists and other subspecialists to ensure appropriate treatment decisions. Discussions about the reproductive impacts on children by much older parents are often given less prominence despite their critical ethical considerations. Factors such as a focus on the efficacy of reproductive technologies and patients' rights to autonomy usually overlook risks to the health and well-being of children. Children of older parents may face

higher health risks and emotional and social challenges, such as losing a parent at a young age or having to care for aging parents. Therefore, comprehensive information and ethical counseling are needed to help patients balance their wishes with responsibilities toward their children.

Chapter 9 discusses ethical considerations regarding the collection and use of posthumous gametes. Ethical challenges include the use of posthumous gametes and embryos for procreation, both those that have been cryopreserved and those that require retrieval. The concerns of physicians and surviving partners can be addressed by having precise consent forms regarding the use of gametes after death. The presence of stored gametes or embryos indicates the existence of a parental project but does not necessarily indicate the deceased's consent to continue the project after death. Cultural differences influence views on posthumous reproduction, with some regions, such as Asia and Israel, being more accepting of posthumous reproduction without formal consent. Explicit instructions from the decedent wishing to continue the parent's project with their spouse reduce ethical concerns as long as those wishes are consistent with those of the surviving spouse. There is no moral obligation for a surviving partner to use preserved gametes or embryos if their partner has died. This decision may be influenced by a variety of reasons, including but not limited to extreme grief, changes in life circumstances, inability to raise children alone, or changes in views about having children. Therefore, the decision not to proceed with the use of preserved gametes or embryos must be respected and understood as the individual right of the surviving partner to choose what is best for him or herself.

Chapter 10 discusses ethical issues related to anonymity in gamete donation and other related matters. Complete anonymity in gamete donation is impossible to guarantee due to technological advances such as online genetic testing and changing social norms. Ethical analysis of gamete donation involves balancing the interests, rights, and obligations of various stakeholders, including medical professionals, clinics, gamete recipients, donors, and resulting offspring, framed within ethical principles such as autonomy, beneficence, nonmaleficence, and justice. The informed consent process should include information regarding the risks of difficulty maintaining anonymity, especially if anonymity is offered as an option to the donor. This is important because, with the development of DNA technology and genetic databases, the donor's identity could be revealed despite the promise of anonymity. In addition, informed consent should cover potential health risks associated with gamete donation, such as the risk of ovarian hyperstimulation (OHSS) in oocyte donors. Donors must be given a detailed explanation of the symptoms, risks, and precautions taken to reduce the likelihood of OHSS. Finally, both donors and recipients must provide up-to-date information regarding severe medical conditions that could impact the child's future health, including a history of genetic diseases and significant health changes during and after the donation process. By covering all of these aspects, the informed consent process can help donors make more conscious and responsible decisions.

3. Evaluation

Some characteristics and strengths of this book include 1) an interdisciplinary approach by bringing together experts from the fields of ethics, law, and medicine to discuss common clinical scenarios in assisted reproduction, thereby providing a comprehensive resource. 2) using narrative ethics, which humanizes the context of moral reasoning and gives voice to the oppressed and marginalized. 3) emphasizes the need for ethical guidance in the rapidly growing field of assisted

reproduction. Designed as an educational resource, this book is a starting point for discussions at various levels of education, including undergraduate, graduate, master's, and doctoral levels. 4) each case in this book is followed by a discussion of medical principles and ethical considerations, reflecting common resolutions in clinical practice.

4. Recommendation

The target audience for this book includes various groups. First, this book is valuable for educational institutions because it is designed as a starting point for discussions at multiple levels of education, whether undergraduate, postgraduate, master's or doctoral. Second, it will be helpful to healthcare professionals, such as doctors and assisted reproduction specialists, to receive ethical guidance through this book. Third, ethics and legal scholars will be interested in the books' interdisciplinary in the legal and ethical framework related to assisted reproduction. Fourth, policymakers can benefit from this book because it discusses disparities in access to fertility treatment and provides recommendations for improving access. Lastly, the general public who wishes to understand the ethical complexities and considerations in assisted reproduction may also find this book very informative.

Acknowledgments

We would like to thank Universitas Kristen Indonesia Maluku for its support, helping to guide and accompany this publication.

Author Contributions

Conceptualization: Vernando Yanry Lameky; Editing: Donny Japly Pugesehan; Proofreading: Agustinus Mathinus Luther Batlajery, Final approval of manuscript: All authors.

Competing Interests

The authors declare that there is no conflict of interest.

References

- Marinelli S, Del Rio A. Beginning of life ethics at the dawn of a new era of genome editing: Are bioethical precepts and fast-evolving biotechnologies irreconcilable? Clin Ter. 2020; 171: 407-411.
- Marinelli S, Del Rio A, Straccamore M, Negro F, Basile G. The armed conflict in Ukraine and the risks of inter-country surrogacy. The unsolved dilemma. Eur Rev Med Pharmacol Sci. 2022; 26: 5646-5650.
- 3. de Mori B, Mercugliano E, Biasetti P, Pollastri I, Spiriti MM, Florio D, et al. The ethical assessment of Assisted Reproductive Technologies (ART) in wildlife conservation. Biol Conserv. 2024; 290: 110423.
- 4. Marinelli S. No more only one mom? European Court of Human Rights and Italian jurisprudences' ongoing evolution. Clin Ter. 2020; 171: e36-e43.

- 5. Zaami S, Del Rio A, Negro F, Varone MC, Marinelli S, Montanari Vergallo G. The March 2021 Italian constitutional court ruling on surrogacy: A prelude to common European legislation for the sake of reproductive health? Eur J Contracept Reprod Health Care. 2022; 27: 61-66.
- Olmedo C, Veiga E, Sánchez L, Ferrer E, Ortiz N, Mauri A, et al. ASEBIR Quality Special Interest Group guidance for quality in assisted reproduction technology. Reprod BioMed Online. 2024; 48: 103730.
- 7. King LP, Band IC. Case Studies in the Ethics of Assisted Reproduction. 1st ed. Cham, Switzerland: Springer; 2023.