Ethics, Medicine and Public Health 33 (2025) 101084

Contents lists available at ScienceDirect

Ethics, Medicine and Public Health

journal homepage: www.sciencedirect.com/journal/ethics-medicine-and-public-health

Review

Ethical dilemmas in voluntary termination of pregnancy with severe congenital anomalies

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ARTICLE INFO

Keywords:
Abortion-Induced
Ethics-medical
Fetus

ABSTRACT

Background: Congenital anomalies (CA) are structural or functional disorders from genetic defects of the fetus occurring in the uterine. However, screening for congenital disabilities to establish a prenatal diagnosis raises many moral considerations and ethical dilemmas in the field of medicine. A detected severe CA consequence to termination of pregnancy in the management option, making it an undoubtful ethical dilemma.

Methods: A literature search was carried out on Indonesian laws, ethical codes, and regulations related to congenital anomalies, utilizing resources such as the Indonesian Medical Association (Ikatan Dokter Indonesia) and the conference proceedings of the Royal College of Obstetricians and Gynecologists (RCOG). An extensive literature search was also utilized from PubMed, Clinical Key, and Elsevier Science journals with specific keywords.

Results: Ethical dilemmas often arise in the context of prenatal diagnosis, which involves a complex process across five distinct stages: disclosure of information to parents, establishing indications for examinations, providing information about a diagnosis, providing psychological and social support, and making diagnostic decisions. The framework proposed by Jonsen, Siegler, and Winslade can be applied to ethical decision-making in the present case.

Conclusion: The choice to terminate a pregnancy due to genetic anomalies or congenital disabilities must comply with the legal bases. The principles of autonomy of each patient and the results of the doctor's decisions have been carefully considered, and the obstetrician must make every effort to respect and protect the dignity of human life.

Introduction

Congenital anomalies (CA) refer to structural or functional abnormalities during embryonic or fetal development. These conditions are present at birth and can affect various organs and body systems. Congenital anomalies can result from genetic or environmental factors or both. According to the World Health Organization (WHO), prenatal screening detects approximately 6% of all congenital malformations before birth. These malformations can affect the development of the brain, heart, spine, limbs, and other body parts. Congenital anomalies are a major global health issue, with hundreds of thousands of babies born each year with these conditions. These anomalies can lead to significant morbidity and mortality, making early detection and intervention critical. Medical technology and research advances have greatly improved our understanding of these conditions and have enabled earlier diagnosis and treatment options for affected individuals [1].

Advancements in modern technology have made it possible to detect congenital anomalies earlier in pregnancy. However, when such anomalies are detected, termination of pregnancy is considered the most viable option, particularly when there is a high risk of stillbirth or neonatal death. Nevertheless, screening pregnant women for congenital anomalies to establish a prenatal diagnosis poses several moral and ethical challenges in the field of medicine. The implications of such a diagnosis can be far-reaching, and it is critical to weigh the potential benefits of early detection against the ethical considerations surrounding the termination of pregnancy [2,3].

Bioethics is an interdisciplinary field that combines the knowledge and methods of various sciences, including philosophy, law, and

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https://doi.org/10.1016/j.jemep.2025.101084
Received 16 December 2024; Accepted 11 March 2025
Available online 29 March 2025

medicine. Its primary goal is to analyze ethical issues that arise in the healthcare sector due to differences in personal and social values and beliefs. One of the most complex and sensitive areas in bioethics is prenatal diagnosis, which involves numerous ethical, social, and legal conflicts in the medical field. This complexity makes it challenging to establish the rights of the fetus and navigate the ethical considerations of prenatal testing and diagnosis. As such, bioethicists play a critical role in helping healthcare professionals and policymakers make informed decisions that balance the rights and interests of all parties involved [3].

The termination of pregnancy on the grounds of congenital defects is considered a violation of the Indonesian Code of Medical Ethics, as stated in article 11, which mandates doctors to do everything possible to alleviate suffering and preserve life, but not to end it. Furthermore, prenatal diagnosis of congenital anomalies or defects remains a contentious issue in Indonesia's diverse society, as it raises ethical considerations. Therefore, it is crucial to establish a clearly defined ethical framework for providing screening and prenatal diagnosis of congenital anomalies or defects. Such a framework should prioritize the well-being of the mother and the fetus while also considering the scientific evidence and ethical implications [4]. This paper aims to explain an in-depth ethical analysis of voluntary termination of pregnancy with severe congenital anomalies in the context of ethics that apply in Indonesia and globally.

Methods

We conducted a comprehensive review of Indonesian laws, ethical codes, and regulations related to congenital anomalies, utilizing resources such as Indonesian Law Number 17 of 2023 concerning Health (*Undang-undang Nomor 17 Tahun 2023 tentang Kesehatan*) [5], Indonesian Government Regulation Number 28 of 2024 concerning Implementing Regulations of Law Number 17 of 2023 concerning Health (*Peraturan Pemerintah Nomor 28 Tahun 2024 tentang Peraturan Pelaksanaan Undang-Undang Nomor 17 Tahun 2023 tentang Kesehatan*) [6], Indonesian Code of Medical Ethics (Kode Etik Kedokteran Indonesia, KODEKI) 2012 by the Indonesian Medical Association (Ikatan Dokter Indonesia) [7], and the conference proceedings of the Royal College of Obstetricians and Gynecologists (RCOG) [8]. Additionally, we conducted extensive literature searches utilizing reputable scientific databases such as PubMed, Clinical Key, and Elsevier Science journals, utilizing keywords such as "ethics", "congenital anomalies", "termination of pregnancy", and "ethical dilemmas".

Results and discussion

Antenatal screening and prenatal diagnosis of congenital anomalies

Screening and diagnostic tests are essential components of antenatal care primarily performed at 20 weeks gestation. These tests aim to identify high-risk pregnancies and serve as effective tools to prevent, detect, and manage potential complications. Antenatal screening typically involves administering questionnaires to evaluate the pregnant woman's medical history and family history of specific conditions. Laboratory investigations, including blood tests and urine analysis, are also routinely performed to assess the health of the mother and developing fetus. Furthermore, ultrasound (US) examinations detect structural anomalies in the fetus and monitor fetal growth. The information obtained through these screening and diagnostic tests is critical to making informed decisions about management strategies and interventions to optimize maternal and fetal health outcomes [9].

Prenatal diagnostics involve advanced techniques such as ultrasonography 4D, chorionic villus (villocentesis), and amniotic fluid (amniocentesis) sampling for DNA analysis. The primary objective of screening and diagnostic testing during pregnancy is to identify the presence of Congenital Abnormalities (CA), which are pathological (or potentially pathological) conditions that manifest before birth. These conditions encompass a broad range of abnormalities, including both genetic and environmental factors, such as genetic disorders like cystic fibrosis, sickle cell disorder, and hemophilia, chromosomal anomalies like Down syndrome, and structural abnormalities like spina bifida. These diagnostic tools are crucial in detecting such abnormalities and providing parents with the necessary information to make informed decisions about their child's care and management [1,10].

Ultrasound screening for prenatal diagnosis has become a common practice in obstetrics. It is an effective tool for detecting fetal abnormalities and is often used by couples to ensure their baby is healthy. However, in cases where a congenital abnormality is discovered, the situation can become complex, and the doctor must approach the issue with a high level of sensitivity and professionalism. The doctor should also consider the patient's cultural background, values, and beliefs while providing accurate information and offering a recommended management plan. The doctor's role is crucial in guiding the parents and ensuring the best possible outcome for the unborn child [11,12].

Termination of pregnancy with congenital anomalies

If routine screening is performed, most congenital anomalies can be identified before 22 weeks of gestation. However, some anomalies can also be detected at later gestational ages, close to labor. To reduce the burden on the physical and mental health of the pregnant woman, termination of pregnancies with congenital defects should be performed no later than 24 weeks gestation. Continuing the pregnancy after 24 weeks will involve greater risk and burden on the family. Moreover, scientific literature supports the ground that around 22–24 weeks, the fetus may acquire autonomous fetal viability. Although first-trimester ultrasounds are improving, the second-trimester scan is still the most crucial for identifying potential fetal abnormalities. While first-trimester scans can detect about half of major issues, the second-trimester scan, typically performed between 18 and 22 weeks, is considered the gold standard. This detailed scan has a high success rate in identifying a wide range of significant structural birth defects [13]. Pregnancy termination is ideally performed before 28 weeks of gestation, before the fetus reaches 1000 g, or when it's clear the fetus cannot survive outside the womb. This is because fetal viability is generally not established until after 28 weeks and a weight of 1000 g; before this point, the fetus is not considered capable of independent life [14]. Screening for fetal anomalies is most effective between 20–22 weeks of gestation. Therefore, clinical practice recommends proceeding with termination at the earliest opportunity, ideally before reaching 24 weeks of gestational age. Performing the procedure sooner may reduce the risk of complications for the mother's reproductive system, and managing the condition and size of the fetus is generally more straightforward at this stage. The decision to terminate a pregnancy with severe congenital anomalies after more than 24 weeks of gestation poses an ethical dilemma to date [8,15].

Ethical review

It is important to consider the array of risks and potential benefits when making decisions related to medical intervention, particularly in cases involving pregnancy and fetal health. From an ethical perspective, these considerations can be summarized under four main principles. Firstly, the principle of beneficence highlights the obligation to protect the patient's welfare, in this case, the fetus. This principle emphasizes the need to maximize the benefits of medical intervention while minimizing the risks of harm. Secondly, the principle of autonomy acknowledges the importance of respecting the patient's values, beliefs, and interests. This principle requires healthcare professionals to obtain informed consent from their patients before implementing clinical management procedures. Informed consent involves providing the patient with detailed information about the type of examination or treatment, as well as any possible risks or injuries that may be associated with

it. Thirdly, the principle of non-maleficence underscores that the decision to terminate a pregnancy voluntarily is conducted under proportionality, particularly in cases where the fetus presents congenital abnormalities that significantly limit life expectancy. This principle further emphasizes the need to avoid misinterpretation regarding the justification for pregnancy termination in such fetal conditions. Finally, the principle of justice emphasizes the importance of treating patients equally, according to their specific needs. This principle underscores the need to provide every patient with the best possible treatment, regardless of their background or personal circumstances. Overall, taking these principles into account can help healthcare professionals make informed and ethical decisions regarding medical intervention in cases involving pregnancy and fetal health [16,17].

In 2010, the RCOG convened a special meeting to discuss the issue of antenatal screening tests to detect fetal anomalies. After thorough deliberation and analysis of scientific evidence, the RCOG concluded that providing all pregnant women with comprehensive information about the purpose, benefits, and potential risks of antenatal screening tests is imperative. This would enable women to decide whether to undergo such tests. The RCOG also emphasized the importance of offering women the opportunity to discuss their options with their healthcare providers before undergoing any screening tests. By doing so, women can make informed decisions that align with their values, beliefs, and preferences while ensuring the best health outcomes for themselves and their babies [8].

Healthcare providers who conduct ultrasound examinations for congenital anomalies must have specialized training to communicate information regarding abnormal findings to women and provide them with proper support throughout the process. In cases where a congenital malformation is identified, termination of pregnancy should be recommended before 24 weeks gestation, as this period provides a safer window for the procedure. After 24 weeks, the risk of failure increases significantly, which can lead to increased physical and emotional trauma and an added burden for the woman. These recommendations align with scientific evidence and best practices in prenatal care [8,15,18,19].

The next question is what is the condition in Indonesia? Based on Law Number 17 of 2023 concerning Health Article 60 "(1) Everyone is prohibited from having an abortion, except with criteria permitted in accordance with the provisions of the Criminal Code" and Government Regulation Number 28 of 2024 concerning Implementing Regulations of Law Number 17 of 2023 concerning Health Article 116 "Everyone is prohibited from having an abortion, except for indications of a medical emergency or for victims of rape or other acts of sexual violence that cause pregnancy in accordance with the provisions of the Criminal Code." and Article 117 "Indications of a medical emergency as referred to in Article 116 include: a. pregnancy that threatens the life and health of the mother; and/or b. the health condition of the fetus with congenital defects that cannot be repaired so that it is impossible to live outside the womb", in which everyone is prohibited from performing an abortion, excluded based on indications of medical emergencies detected early in pregnancy, either threatening the life of the mother and/or fetus suffering from severe genetic diseases and/or congenital defects, or which cannot be repaired so that it makes it difficult for the baby to live outside the womb. However, the Law on Health provides a limitation in Article 76: it can only be carried out before six weeks of pregnancy, calculated from the first day of the last menstruation, except in the case of medical emergencies by health workers who have the skills and authority who have a certificate determined by the Minister and the consent of the pregnant woman and her husband [5]. Law Number 17 of 2023 concerning Health Article 60 states, "… (2) The implementation of abortions with the permitted criteria as referred to in paragraph (1) may only be carried out: (c) with the consent of the pregnant woman concerned and with the consent of the husband, except for rape victims." [5]. Furthermore, the Regulation of the Minister of Health Number 3 of 2016 concerning Training and Provision of Abortion Services for Emergency Medical Indications and Pregnancy Due to Rape, Article 12 "…(2) Safe, quality and responsible abortion services include: c. with the husband's permission, except for rape victims; (3) In the event that the husband's permission as referred to in paragraph (1) letter c cannot be fulfilled, approval can be given by the family of the pregnant woman concerned…" [20]. The primary responsibility rests with the mother in informed consent and informed choice. However, to enhance the decision-making process, the physician also seeks the husband's approval and may involve input from other close family members to corroborate the decision. If performed at 4 months of pregnancy, it is illegal and violates the provisions of Article 194 of the Health Law Number 36 of 2009 [21]. Law Number 1 of 2023 concerning the Criminal Code Article 463 "…(1) Every woman who has an abortion shall be punished with a maximum imprisonment of 4 (four) years. (2) The provisions as referred to in paragraph (1) do not apply if the woman is a victim of a criminal act of rape or other criminal act of sexual violence that results in a pregnancy that is not more than 14 (fourteen) weeks old or has indications of a medical emergency…" [22]. Majelis Ulama Indonesia (MUI) Fatwa Number 4 of 2005 concerning Abortion "(1) Abortion is forbidden by law since the implantation of blastocyst in the mother's uterine wall (nidation). (2) Abortion is permitted because there is an excuse, either an emergency or a necessity. a. Emergency circumstances related to pregnancy that permit abortion are: 1) Pregnant women suffer from serious physical illnesses such as advanced cancer, tuberculosis with caverna and other serious physical illnesses that must be determined by a team of doctors. 2) In circumstances where the pregnancy threatens the mother's life. b. Emergency circumstances related to pregnancy that can permit abortion are: 1) The fetus is detected to suffer from a genetic defect that if born later will be difficult to cure. 2) Pregnancy resulting from rape as determined by an authorized team that includes, among others, the victim's family, doctors, and religious scholars. c. The permissibility of abortion as referred to in letter (b) must be carried out before the fetus is 40 days old" [23]. Certain Islamic scholars suggest that Islamic law allows for abortion prior to 120 days of gestation, which is recognized as the point at which personhood, or "ensoulment," is believed to begin. This timeframe is particularly important because if the diagnosis of fetal anomalies occurs after this 120-day threshold, terminating the pregnancy may be deemed impermissible under Islamic jurisprudence. Delays in diagnosis can lead to substantial challenges for both parents and children [24].

Article 11 of the Indonesian Code of Medical Ethics (Kode Etik Kedokteran Indonesia, KODEKI) 2012, emphasizes the importance of careful consideration by doctors in the diagnosis, treatment and prognosis of patients in the context of reproductive life. This includes various advancements in reproductive technology that can reduce or eliminate human suffering while maintaining the individual's dignity. Furthermore, the article affirms that doctors must preserve life and alleviate suffering rather than end it. These principles are rooted in scientific research and ethical guidelines, which guide doctors in providing the best possible care for their patients [7].

According to a recent study, the ethical considerations surrounding maternal autonomy and beneficence must also extend to the fetus's well-being, because fetal well-being in terminating pregnancies with lethal anomalies involves considering whether termination aligns with the fetus's best interests by preventing potential suffering. However, defining "fetal well-being" in these situations is complex. It requires balancing the potential for physical suffering with the inherent value of any human life, even with significant limitations. While preventing suffering is a crucial consideration, it must be weighed against the ethical implications of denying a fetus any chance of existence, however limited. However, this can be challenging in countries like Indonesia, where the Medical Practice Act is based on patient autonomy, beneficence, and non-maleficence. In such cases, healthcare providers must thoroughly discuss with patients to ensure the best possible medical and ethical decisions are made. This approach aligns with the principles of evidence-based medicine, which emphasizes the importance of

integrating clinical expertise, patient values, and the best available evidence to guide clinical decision-making [25].

Chronology of the ethical dilemma

Ethical dilemmas often arise in the context of prenatal diagnosis, which involves a complex process that occurs across five distinct stages. At the first stage, when disclosing information to parents, it is important to ensure that the information provided is tailored to the couple's specific needs and the available methods of diagnosis. Typically, an ultrasound examination is performed, and the content of the information should be clear, comprehensive, continuous, understandable, and consistent. If the patient refuses further examination, they should sign a refusal letter. The second stage involves establishing indications for examinations, which are determined based on the patient's medical history, maternal-fetal pathology, and specific protocols. The selection of the type of examination is rational and based on the indication and experience of the doctor, and consent from the couple is required. The third stage involves providing information about a diagnosis, which is a sensitive matter that requires a doctor competent in their field to communicate the diagnosis verbally to the patient and in writing in the form of examination results. The information should be conveyed in a way that the spouse can easily understand, particularly in cases of pathological diagnosis. If necessary, psychological and social support should be provided, which is not always available in most hospitals. The fourth stage involves providing psychological and social support to the patient and their family as they come to terms with the diagnosis. It is important to ensure that the patient and their family have access to the resources they need to cope with the situation and that the information provided is clear, complete, and appropriate to their circumstances. Finally, in the fifth stage, diagnostic decisions are made based on a primary diagnosis, and alternative courses of action are suggested. Before terminating a pregnancy, a thorough examination should be conducted, and the results should be consulted with other relevant departments. The hospital ethics committee should evaluate the risks and benefits of each decision and option, and the information provided to the couple about the different possibilities and options should be easy to understand, clear, complete, and appropriate to their circumstances. Doctors should fully respect the decisions made by the patient and the couple within the limits of the law [2,3,9,10,26].

In Indonesia, the issue of abortion is multifaceted, involving legal, ethical, and religious considerations. Generally, abortion is prohibited; however, exceptions exist in specific circumstances, such as severe congenital anomalies that are incompatible with life or situations involving medical emergencies. A pivotal aspect of this discourse is the gestational age limit, which serves as a reference point for decision-making regarding abortion. Discrepancies exist among legal statutes, religious edicts (fatwas), and medical practices within the country. Legally, abortion in Indonesia is primarily permitted up to 14 weeks of gestation in cases of rape or medical emergencies. Religious fatwas may also allow for abortions in instances of significant genetic defects or pregnancies resulting from rape, typically before the fetus reaches 40 days of development. However, other interpretations extend this limit to 120 days. Conversely, in clinical practice, the termination of pregnancies involving severe congenital anomalies is often considered up to 24 weeks of gestation, taking into account the health of both the mother and fetus. This approach is supported by scientific literature indicating that fetal viability outside the womb may be achieved around 22–24 weeks of gestation.

The variations in gestational age limits present substantial ethical challenges. On one side, there is a strong inclination to uphold the sanctity of life beginning at conception. Conversely, there are apprehensions regarding the quality of life for a fetus with significant abnormalities, as well as the potential impact on the mother's well-being if the pregnancy is allowed to persist.

Ethical decision making

Ethical decision-making is a critical aspect of providing quality healthcare in clinical settings. One approach to ethical decision-making is the framework proposed by Jonsen, Siegler, and Winslade, which comprises four topics. The first topic is Medical Indication, which involves assessing the ethical implications of medical interventions based on the principles of beneficence and non-maleficence. Informed consent is also an essential component of this topic, as patient preferences and autonomy are considered when deciding on the benefits and burdens of treatment. The second topic is Patient Preferences, when the will of the mother and husband differ, and the mother's autonomy is key. The mother has the right to decide about her body and pregnancy, although the husband plays an important role in providing support. The welfare of the mother and fetus also needs to be considered, where terminating the pregnancy may be necessary to protect the mother's physical and psychological health or to reduce the suffering of the fetus if the anomaly is severe. The third topic is Quality of Life, which focuses on the ethical considerations related to prognosis and the goals of medicine. Assessing the patient's quality of life is crucial to ensure that medical interventions promote, maintain, or enhance their well-being while still adhering to the principles of beneficence, non-maleficence, and autonomy. The fourth topic is Contextual Features, which involves the ethical considerations related to the patient's social, cultural, and environmental factors. This fourth topic emphasizes that medical decision-making is inseparable from family considerations or factors. In this case, the patient's husband and/or parents are still explained and asked for approval even though the absolute right to autonomy lies with the patient (wife). In addition, the culture in Indonesia, which still adheres to patriarchal beliefs, makes the husband culturally hold the responsibility in decision-making. When dealing with these features, principles of loyalty and fairness are essential to ensure that healthcare professionals provide equitable and just care. In the context of decisions regarding pregnancy termination, healthcare professionals must evaluate two critical components: the medical rationale for the necessity of the procedure and the ethical considerations that influence decision-making. These elements ensure that physicians maintain trust and confidence in their professional judgments, which should align with the patient's and her family's explicit and informed choices. This approach upholds the principles of loyalty and fairness in the decision-making process. Overall, using the Jonsen, Siegler, and Winslade framework can help healthcare professionals navigate complex ethical issues and ensure that they make decisions that are in the best interests of their patients while respecting their autonomy and promoting fairness [27].

Conclusions

In cases of termination of pregnancy with severe congenital abnormalities, doctors make decisions and perform termination actions with medical considerations (medical indications) to be better for the mother (beneficence, non-maleficence, and quality of life) by giving a position of respect for the patient's rights in deciding after informed consent informed choice (autonomy, patient preference) also looking at other aspects that are involved in making this decision (contextual features). Medical, ethical, and legal considerations are considerations in decision-making in ethical dilemmas. Ethical dilemmas in voluntary termination of pregnancy with severe congenital anomalies arise from the complex interplay of medical, personal, legal, sociocultural, and religious factors. While medical expertise informs decisions, the ultimate choice is often a deeply personal moral, constrained by legal regulations, societal values, and individual beliefs. A core tension exists between respecting patient autonomy (the mother's right to choose) and the perceived right to life of the fetus, particularly in cases of lethal anomalies. Ethical decision-making necessitates carefully balancing medical indications, patient preferences, quality of life considerations, and contextual factors, guided by ethical principles and adherence to relevant laws. Critically,

time is of the essence, as delays in diagnosis and intervention can severely limit a woman's options due to legal restrictions on gestational age for termination. This underscores the importance of early detection and timely access to care for mothers facing such difficult choices.

CRediT authorship contribution statement

NAM is the first author, he conceptualized, designed, and wrote the paper, in cooperation with TI and MA.

Patient consent for publication

Not required.

Provenance and peer review

Not commissioned; externally peer reviewed.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author(s) used GRAMMARLY in order to rephrase and improve the manuscript language quality. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the published article.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgment

The authors acknowledge Farhamna Academic for assisting in preparing this manuscript.

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