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The Ethical Implications of Genetic Testing Perspectives in Nursing Practice: Comprehensive Review

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Abstract

Background: The rapid advancements in genetic testing and genomic healthcare have prompted significant ethical considerations within nursing practice. As genetic technologies evolve, nurses increasingly encounter ethical dilemmas related to patient autonomy, informed consent, confidentiality, and equity in access to genetic services.

Methods: This comprehensive review analyzes literature published between 2016 and May 2023, focusing on the ethical implications of genetic testing, counseling, and therapeutics in nursing. Databases such as ScienceDirect and Google Scholar were utilized, employing keywords including "genetic testing," "nursing ethics," and "genetic counseling."

Results: The findings reveal that autonomy is a predominant ethical concern, often compromised due to inadequate patient education and the influence of familial and societal pressures. Barriers to informed consent, such as insufficient time for decision-making and lack of transparency from healthcare providers, hinder patients' ability to make informed choices. Additionally, confidentiality issues arise from unauthorized access to genetic information, posing risks of discrimination and stigmatization. The review also highlights disparities in access to genetic services, particularly for marginalized populations, underscoring the need for equitable healthcare practices.

Conclusion: The ethical challenges associated with genetic testing in nursing practice necessitate enhanced education and training for nurses in genomics. By integrating genetic competencies into nursing curricula and ongoing professional development, nurses can better support patients in navigating the complexities of genetic information. This approach will promote patient autonomy, ensure informed consent, and advocate for equitable access to genetic services, ultimately improving patient care in the genomic era.

Keywords: Genetic testing, nursing ethics, patient autonomy, informed consent, healthcare equity.

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1. Introduction

The Human Genome Project has facilitated a deeper comprehension of the correlation between human genes and illness via the comprehensive mapping of the whole human genome. Advancements in genetic technology have initiated a transformation in the medical health system regarding diagnosis, treatment, and genetic counseling (1). The concept of genomic healthcare has arisen, characterized as care founded on genomic information and technologies to facilitate earlier diagnosis, risk assessment, and treatment options for genetic disorders. Consequently, genomic healthcare enhances quality and patient safety, diminishes costs, and improves health outcomes (2).

Genetic technologies facilitate the direct detection of illnesses, the formulation of medicines tailored to individual genetic flaws, and the delivery of genetic counseling to patients to mitigate disease transmission (3). Genetic testing identifies DNA abnormalities that may result in pathological conditions by assessing the likelihood of illness development and transmission to progeny (4). Genetic treatments are transformative interventions that target the root causes of illnesses by modifying gene expression or rectifying defective genes (5). Genetic counseling is a communicative process that enables patients and families to make independent choices and use new genetic knowledge more efficiently. Patch and Middleton (3). Genetic counseling assists patients in comprehending and adjusting to the biopsychosocial ramifications of the condition. This procedure includes the analysis of the family's medical history to evaluate the emergence or incidence of illness, education on heredity, testing, prevention, and counseling for informed decision-making (6).

The incorporation of genetic testing, treatment, and genetic counseling into healthcare has impacted nurses and other healthcare professionals. Nurses are progressively engaging with genetic advancements that impact clinical nursing care, hence augmenting their ethical obligations and roles in genetic counseling (7). This study aims to critically examine ethical concerns related to genetic testing, genetic counseling, and genetic therapeutics within nursing care, by ethical norms.

2. Methods

The ScienceDirect and Google Scholar databases were used to locate original research publications published between 2016 and May 2023 that assessed ethical problems about genetic testing, genetic therapeutics, and genetic counseling in nursing care. The terms "genetic techniques," "genetic testing," "genetic therapies," "genetic counseling," "principle-based ethics," "nursing ethics," and "nursing care" were used in the study.

3. Independence

The idea of ethical autonomy emphasizes individual liberty and the ability to act with awareness. The notion of autonomy encompasses four dimensions: self-determination, freedom, independence, and the realization of one's objectives (8). A study indicated that adequate professional training for genetic counselors, offering emotional support to patients, ensuring patient comprehension of information, securing informed consent, considering familial influences, and addressing genetic discrimination were effective in enhancing patient autonomy. Two investigations highlighted the need for non-directive genetic counseling to maintain patient autonomy and prevent medical paternalism (9,10). Research on soft paternalism indicates that patients' options may be somewhat restricted when acceptability and utility are elevated (11). A study report indicated that genetic counseling influences the decision-making processes of patients accompanied by relatives who have had identical treatment protocols. This condition might be advantageous for decision-making, although it can also complicate individual decision-making (12).

Informed consent in clinical care honors patients' rights to independently engage in medical decision-making after a thorough evaluation of potential risks and benefits and seeks to empower people to get treatment aligned with their health objectives (13). In a research article regarding amniocentesis, patients lack valid consent due to insufficient decision-making time, inadequate knowledge about genetic testing, insufficient information from healthcare professionals, the stress of potential fetal anomalies, and the risk of fetal loss. In the same research, an instance of this occurs when a patient instructs the genetic consultant to proceed as they see fit (14).

A study paper on whole genome sequencing in pediatric patients highlights that although patient benefit is crucial for long-term health, the child's autonomy in decision-making is paramount. An ethical issue emerges between autonomy and nonmaleficence from this viewpoint. In the same article, children who cannot decide to accept or reject therapy may experience a violation of autonomy when their parents make this choice on their behalf. Parents and health professionals prioritizing a child's well-being may overlook the child's autonomy (15). Another study report on Shared Decision Making (SDM) indicated that SDM enhances patient autonomy, improves comprehension of medical alternatives, maximizes benefits, and minimizes damage by facilitating the evaluation of risks and advantages. (16).

A study report indicates that while autonomy and anonymity are maintained in pharmacogenetic testing, this may result in the revelation of genetic information. To circumvent this ethical quandary, stringent secrecy is essential to exclude any information from being disclosed without the patient's agreement. Healthcare workers must adhere to the concept of secrecy and refrain from disclosing any information unless stipulated in informed consent and authorized by the patient (17). The two publications highlight that healthcare practitioners lack proficiency in genetic testing and fail to furnish patients with the necessary information. Consequently, patients lack awareness of the advantageous and detrimental aspects of the tests, complicating the acquisition of informed permission and perhaps infringing against the concept of autonomy. Genetic counseling is crucial in mitigating ethical dilemmas. Simultaneously, individuals may encounter decision-making challenges stemming from religious convictions that contradict medical information (18,19).

4. Confidentiality

Nurses are required to maintain the confidentiality of patient information and must not share it with any other party without the patient's permission (20). Patients' medical information includes not only clinical exams and test findings but also their views of family life, lifestyle, and habits. Improper publication of this information might jeopardize a patient's reputation, prospects, and human dignity (21).

In a study paper on amniocentesis, scientists and health professionals expressed concerns over the publication of genetic information and data privacy (14). Unauthorized access to genetic information may occur, and such information may be released and used for reasons outside healthcare (22). Another study article indicates that genes contribute to stigmatization and prejudice. Although the prevention of genetic illnesses is seen as beneficial, what happens if a mother, who is a carrier, takes her own life? Further research highlighted that genetic testing might lead to significant repercussions, perhaps resulting in stigma for individuals, beginning with a single family member; however, disseminating this knowledge can mitigate damage (23). These instances highlight the ethical conflict between the utility of genetic testing and the ideals of privacy and non-maleficence (15).

5. Beneficence and non-maleficence

The notion of beneficence emphasizes patient welfare via ethical guidelines. The patient's benefit supersedes other considerations. This ethical concept advocates for patient rights mitigates damage, eliminates detrimental practices in therapeutic settings, supports marginalized groups, and protects individuals in peril. In contrast to nonmaleficence, beneficence necessitates a positive approach. The idea advocates for not only the avoidance of damage but also the enhancement of patient welfare and well-being (20).

The concept of nonmaleficence emphasizes the avoidance of damage to the patient. This concept mandates moral imperatives that prohibit damage, neutralization, offense, infliction of pain, suffering, death, and the deprivation of patients' pleasure in life. This concept dictates that nurses must guarantee that the benefits surpass the risks and harms associated with nursing care (20). Genetic counseling should aim to reduce bias against genetic testing, which facilitates early illness identification (14, 24).

Research done in Lebanon and Quebec highlights that noninvasive prenatal testing differentiates individuals with genetic variations, resulting in a decreased population of individuals with impairments, who then encounter heightened discrimination and stigmatization. Furthermore, the research indicated that male partiality is prevalent in these nations, suggesting that this test may contribute to gender discrimination, perhaps resulting in the demise of several female infants (18). These cases demonstrate violations of the ethical norms of beneficence, nonmaleficence, and fairness.

A study report on whole genome sequencing in pediatric patients highlighted the inability of health practitioners to elucidate all aspects of genetic testing, resulting in parents making choices without a comprehensive awareness of the associated risks and benefits. This contravened the principles of beneficence and nonmaleficence. The study report indicates that genetic testing may adversely affect an individual's life by forecasting future ailments in those who are now healthy (15).

6. Equity

The idea of justice emphasizes the equitable, fair, and unbiased allocation of health services to all individuals, ensuring that patients get equal treatment without discrimination in care delivery. Nurses are tasked with ensuring equitable allocation of labor, time, and resources in the delivery of nursing services (25).

Parents of children diagnosed with cystic fibrosis encountered disparities in access to genetic counseling (26). Parents of autistic children often cannot get genetic testing owing to prohibitive expenses, resulting in delayed diagnoses and exacerbated challenges (27). Furthermore, noninvasive prenatal testing in Lebanon is not included in the healthcare system, resulting in inequities and economic obstacles for individuals (18).

Obtaining genetic diagnosis, treatment, and counseling is challenging for several susceptible individuals. This discrepancy may be mitigated by optimizing current resources to enhance nurse literacy in genomics, including related ethical, legal, and social concerns (28). Nurses should spearhead the incorporation of genetic diagnosis, treatment, and counseling into the healthcare system to guarantee equitable access for all societal segments, promoting patient engagement with necessary resources and overseeing resource management in their capacities as managers and consultants.

7. Deliberation

This review research aimed to rigorously evaluate genetic testing, counseling, and therapies in nursing care following ethical norms. The notion of autonomy was the most extensively addressed topic in the studied papers, according to the present review findings. The principle of autonomy is likely to be compromised in individuals who are young, possess limited knowledge and understanding of genetic testing, treatments, and counseling, experience pressure from high risks and time constraints, lack the right to choose and provide informed consent, interact with health professionals who fail to offer sufficient transparency and exhibit a lack of genetic knowledge, do not receive genetic counseling, and hold religious beliefs that conflict with medical information. The conflict between autonomy and nonmaleficence, with privacy, constituted the predominant ethical issue. Upon examining the literature review research, findings congruent with the present study's conclusions were identified. A review analyzing genetic testing and counseling through an ethical lens concerning autonomy determined that the role of a guide in genetic counseling, insufficient education in medical genetics, and the influence of social, religious, and cultural beliefs on decision-making affect access to genetic health services (4).

Research indicates that nurses and physicians possess insufficient knowledge and abilities about genetics in medical treatment (29,30). Furthermore, a study indicates that nurses insufficiently exhibit their abilities to deliver holistic care to individuals with genetic illnesses (31). A study indicates that nurses are not adequately fulfilling essential abilities, such as assessing three generations of family history, creating a pedigree, and comprehending the links between genetics and genomics. (32). This review study demonstrated that when nurses and other healthcare professionals inadequately deliver genetic testing and counseling, they fail to educate effectively, lack transparency, restrict patient autonomy, and hinder informed decision-making.

The present analysis indicates that young children, who rely on their parents, do not exhibit autonomy in genetic testing. Likewise, the evidence indicates that individuals with neurodegenerative disorders have similar autonomy challenges (33). In such situations, genetic testing has to be conducted when substantial health issues arise and, in the patient's, best interest (34). Moreover, breaches of the autonomy principle can be mitigated through the provision of educational resources, such as videos and forms, tailored to the comprehension levels of children and their parents regarding genetic testing, while simultaneously enhancing the child's involvement in decision-making, thereby enabling parents to make choices without infringing upon the child's autonomy (35).

Religion and culture may serve as impediments to independent decision-making. In the present study, mothers who gave birth to handicapped children opted for an abortion if the fetus was female. Religion and culture may impede the capacity for independent decision-making. In the current research, mothers delivered infants with defects to circumvent religious objections, however opted for abortions if the fetus was female due to societal masculine preference. Literature indicates that religious views oppose abortion and genetic services (4). Carriers are marginalized and culturally stigmatized. Both society and health professionals used accusatory language against carrier persons (4, 36).

The present research indicates that patients' decision-making is influenced when they possess little information and awareness of genetic testing and lack sufficient time. One study indicates that patients perceive genetic knowledge as challenging and uninformative. To safeguard the patient's autonomy and facilitate informed decision-making, the permission document's wording must align with the patient's health literacy (37). The patient is unable to comprehend information that has not been elucidated to them. Consequently, the informed consent procedure must provide comprehensive, lucid, and transparent information (38).

Nurses must articulate the goal of a genetic test, its outcomes, limits, side effects, and potential treatment choices, and provide patients access to supplementary resources while obtaining informed consent (39). To achieve effective informed consent, patients must be allotted sufficient time, permitted to thoroughly read the form, comprehend the procedures involved in genetic diagnosis and treatment, and allowed to pose questions and receive answers (40-42).

8. Conclusion

This research indicated that nurses may face several ethical dilemmas in genetic diagnosis, treatment, and counseling, particularly those about the concept of autonomy. As genetic technology advances throughout healthcare, nurses must stay informed on genetic breakthroughs related to diagnosis and treatment to provide optimal nursing care. Nurses must enhance their genetic counseling competencies with an ethical framework that accurately educates patients, presents suitable alternatives, and honors patient autonomy by fulfilling their responsibilities as educators and counselors. The genetic competencies of nurses should be enhanced by including genetics courses in nursing school and by integrating genetic disorders, testing, treatments, and counseling into in-service training for nurses. Genomic nursing research may potentially concentrate on enhancing genetic proficiency among nurses.

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الآثار الأخلاقية لاختبار الجينات: وجهات نظر في ممارسة التمريض: مراجعة شاملة

الملخص

الخلفية :أدت التقدمات السريعة في اختبار الجينات والرعاية الصحية الجينومية إلى ظهور اعتبارات أخلاقية كبيرة ضمن ممارسة التمريض. مع تطور تقنيات الجينات، يواجه الممرضون بشكل متزايد معضلات أخلاقية تتعلق باستقلالية المرضى، والموافقة المستنيرة، والسرية، والعدالة في الوصول إلى خدمات الجينات.

الطرق :تحلل هذه المراجعة الشاملة الأدبيات المنشورة بين عامي 2016 ومايو 2023، مع التركيز على الآثار الأخلاقية لاختبار الجينات، والاستشارة، والعلاج في التمريض. تم استخدام قواعد بيانات مثل ScienceDirect وGoogle Scholar، مع استخدام كلمات رئيسية تشمل "اختبار الجينات"، "أخلاقيات التمريض"، و"الاستشارة الجينية."

النتائج :تكشف النتائج أن الاستقلالية هي قضية أخلاقية بارزة، وغالبًا ما تتعرض للخطر بسبب عدم كفاية تعليم المرضى وتأثير الضغوط العائلية والاجتماعية. تعيق الحواجز أمام الموافقة المستنيرة، مثل عدم كفاية الوقت لاتخاذ القرار وغياب الشفافية من مقدمي الرعاية الصحية، قدرة المرضى على اتخاذ خيارات مستنيرة. بالإضافة إلى ذلك، تنشأ قضايا السرية من الوصول غير المصرح به إلى المعلومات الجينية، مما يطرح مخاطر التمييز والوصم. كما تسلط المراجعة الضوء على الفجوات في الوصول إلى خدمات الجينات، خاصة بالنسبة للسكان المهمشين، مما يبرز الحاجة إلى ممارسات رعاية صحية عادلة.

الاستنتاج :تتطلب التحديات الأخلاقية المرتبطة باختبار الجينات في ممارسة التمريض تعزيز التعليم والتدريب للممرضين في مجال الجينوميات. من خلال دمج الكفاءات الجينية في المناهج الدراسية للتمريض والتطوير المهني المستمر، يمكن للممرضين دعم المرضى بشكل أفضل في التنقل عبر تعقيدات المعلومات الجينية. ستعزز هذه الطريقة استقلالية المرضى، وتضمن الموافقة المستنيرة، وتدافع عن الوصول العادل إلى خدمات الجينات، مما سيؤدي في النهاية إلى تحسين رعاية المرضى في عصر الجينوم.

الكلمات المفتاحية :اختبار الجينات، أخلاقيات التمريض، استقلالية المرضى، الموافقة المستنيرة، عدالة الرعاية الصحية.