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Ethical Considerations in Global Health Informatics: Navigating the Intersection of Medicine and Technology

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ABSTRACT

Health informatics operates at the intersection of medical practices and technological advancements, necessitating a nuanced understanding of ethical considerations. This article delves into the historical antecedents of medical and informatics ethics to provide a comprehensive context for discussing contemporary ethical dilemmas in global health informatics. It traces the roots of medical ethics to pivotal events like the Nuremberg trials, emphasizing principles of voluntary consent, patient safety, and respect for individual rights. The development of informatics ethics paralleled the increasing ethical awareness regarding data utilization and technical progress. Health informatics ethics arose naturally, with ethical norms highlighting values like privacy, secrecy, and non-maleficence. This article explores the ethical considerations of using health information technologies in various socio-cultural situations through historical studies, regulatory frameworks, and case studies. It highlights the ongoing tension between ethical principles, cultural norms, and legal frameworks in shaping ethical decision-making in the digital age. Despite challenges, embracing ethical principles remains paramount for health informatics professionals to navigate the complexities of digital healthcare delivery with integrity and compassion, ultimately advancing the ethical practice of medicine in the modern era.

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1. Introduction

In the rapidly evolving healthcare landscape, the intersection of medical practices with technological advancements has given rise to health informatics. Health informatics amalgamates insights from both medical and informatics disciplines, necessitating a nuanced understanding of ethical considerations that underpin its development and application (Kaliyah, 2023). The roots of medical ethics trace back to pivotal events such as the Nuremberg trials, where the atrocities committed by the Nazi regime highlighted egregious violations against humanity, particularly within the medical profession (Brody, 2014). The Nuremberg Code, a seminal document emerging from these trials, underscored the principles of voluntary consent, patient safety, and respect for individual rights, setting a foundational framework for ethical medical research and practice (Boyd, 2007).

Simultaneously, the advent of informatics ethics began to gain traction, notably marked by Norbert Wiener's seminal work on the societal implications of human-machine interactions. From the formulation of ethical principles by pioneers like Kostrewski and Oppenheim to the delineation of information ethics by Severson, the evolution of informatics ethics mirrored the growing ethical consciousness surrounding data usage and technological advancements.

Throughout the latter half of the 20th century, as computing capabilities burgeoned, professional organizations promulgated codes of ethics emphasizing privacy, confidentiality, and non-maleficence (Du & Xie, 2021). The alignment of these principles with those entrenched in medical ethics underscores the ethical nexus between the two disciplines.

Against this backdrop, the emergence of health informatics ethics was inevitable. Principles enshrined in codes of ethics for health information professionals, such as those delineated by the "International Medical Informatics Association" (IMIA), reflect a confluence of medical and informatics ethics (Gibson et al., 2015). With an emphasis on safeguarding patient privacy, ensuring data accuracy, and mitigating harm, these codes serve as guiding beacons for ethical conduct within the burgeoning field of health informatics. This study aims to investigate the ethical aspects of health informatics worldwide.

The author aims to explore the intricate landscape of ethical considerations in using health information technologies in various socio-cultural settings by examining past examples and current ethical principles. The author aims to offer insights on ethical decision-making and responsible practices in global health informatics by thoroughly examining ethical principles, regulatory frameworks, and case studies. With the merging of medicine and technology, it is crucial to prioritize ethical principles. Through a thorough analysis of the historical developments of medical and informatics ethics, we can gain a deeper understanding of the ethical principles that form the basis of ethical issues in global health informatics. This research aims to add to the current discussion on ethical practices in using technology to improve healthcare delivery worldwide. This essay explores the historical origins of medical ethics and informatics.

2. Ethical Landscape of Global Health Informatics

The ethical terrain within the domain of global health informatics is multifaceted and influenced by many factors, including legal frameworks, cultural norms, and societal values Robson et al., 2019). While there is a tendency to conceptualize the development of ethical standards as a linear progression towards universal acceptance, the reality is far more nuanced and contingent upon diverse perspectives shaped by historical contexts and geographical locations.

Within ethical discourse, three prevailing views regarding the interplay of ethics, law, culture, and society emerge, each with distinct implications for moral conduct. The first perspective, called legalistic ethics, posits that ethics are subordinate to the law and primarily designed to uphold the societal order as defined by prevailing legal statutes (Wendel, 2005). In this view, ethical behavior is synonymous with compliance with existing legal frameworks and societal norms.

Contrastingly, the perspective of Cultural and Legal Extensionism acknowledges the influence of cultural norms and legal structures on ethical considerations, recognizing them as integral components shaping ethical conduct. While ethical obligations may extend beyond legal mandates, they are fundamentally informed by the broader cultural and legal context within which they operate (Berger-Walliser & Scott, 2018). However, adherence to ethical principles must never contravene legal requirements, ensuring alignment between ethical imperatives and legal obligations. A third viewpoint, often called Personal Conscience Ethics, emphasizes the autonomy of individual ethical judgment, positing that ethical obligations are not contingent upon external legal or societal dictates but rather emanate from an innate moral responsibility. Consequently, ethical decisions are guided by personal convictions and principles, even in the face of conflicting legal requirements.

Despite internationally recognized ethical frameworks such as the Nuremberg Code and the Declaration of Helsinki, applying ethical principles in practice presents significant challenges and contradictions (Schmidt, 2023). Historical precedents underscore instances where ethical standards have been inconsistently upheld globally, with cultural variances and legal disparities contributing to ethical dilemmas. Furthermore, conflicts between legal requirements and ethical imperatives often present complex ethical quandaries for practitioners, necessitating careful navigation and critical reflection.

In global health informatics, navigating ethical complexities demands a nuanced understanding of legal frameworks, cultural nuances, and moral principles (Moorthie et al., 2022). While adherence to internationally recognized codes of ethics provides a foundational framework for ethical practice, it is essential to cultivate contextual sensitivity and critical reflexivity to address the multifaceted ethical challenges inherent in health informatics. By acknowledging and navigating the intricate interplay between legal, cultural, and societal factors, practitioners can foster ethical conduct and ensure the responsible utilization of health information technologies globally.

3. International Health Informatics Ethics Codes and Directives

Across various nations and regions, distinct codes of ethics and directives govern the ethical conduct of health informatics professionals. These frameworks underscore the importance of ethical considerations in utilizing health information technologies and protecting patient data. Here are some notable examples:

American Medical Informatics Association (AMIA)

The AMIA Code of Ethics highlights the importance of confidentiality, information security, and ethical interactions between healthcare providers and patients. Although shorter than specific global standards, this code focuses on ethical responsibilities towards individual patients and society, emphasizing ideals rather than strict rules (Detmer, Abner & Greenwood, 2009).

United Kingdom

The UK Council for Health Informatics Professions (UKCHIP) in the UK establishes guidelines for the conduct of health informatics professionals, emphasizing professional standards, respect for individuals' rights, and the advancement of the profession's standards and reputation (Walpole, Taylor & Banerjee,

2016). The UK's General Medical Council (GMC) provides ethical guidance for healthcare workers under its Good Medical Practice standards.

European Parliament Directives

The European Parliament Directives, including (95/46/EC) and its revisions, enforce mandatory rules on data protection in European Union member countries (Hustinx, 2013). The guidelines address several topics including privacy and security, and establish principles including fair and legitimate handling of personal data, data accuracy, and proper security protocols.

International Guides

Several global medical organizations have created guidelines focusing on particular health informatics tasks, such as electronic health records and physician-patient email correspondence (Lai et al., 2017). The American Medical Association's Guidelines for Physician-Patient Electronic Communications and Australia's Guide to Electronic Communication in Healthcare cover ethical considerations such data privacy and protection.

Interdisciplinary Ethics Guides

Additionally, ethical guidelines from several disciplines connect with health informatics ethics, impacting ethical considerations in the field. The instructions illustrate the ethical framework in which health informatics functions, highlighting the significance of ethical standards in many professional fields.

In sum, these international health informatics ethics codes and directives highlight the global commitment to ethical conduct in the utilization of health information technologies. By adhering to these frameworks, professionals can navigate ethical challenges and uphold the integrity and trustworthiness of healthcare systems worldwide.

4. Ethical Complexities in Health Informatics

Amidst the intricate interplay of ethics, laws, and cultural influences in health informatics, several core ethical principles emerge as guiding beacons for professionals in navigating ethical dilemmas and ensuring the integrity of their practice. These principles encapsulate fundamental values such as privacy, informed consent, data security, integrity, and accountability. Patients' inherent right to privacy underscores the necessity for Health Informatics Professionals (HIPs) to refrain from sharing information without valid justification or consent. Moreover, safeguards must be in place to prevent excessive collection of personal data, ensuring that only necessary information is obtained. HIPs bear the responsibility of maintaining the security of patient data, promptly addressing security concerns even if beyond their direct control. Data integrity entails ensuring accuracy, currentness, and truthful presentation without manipulation. Informed consent is paramount, requiring patients to be fully informed about procedures and research participation, with any deviation necessitating obtaining new consent. HIPs must be cognizant of relevant laws and regulations, navigating conflicts between professional ethics and legal mandates when necessary. Furthermore, health informatics ethics align with broader medical ethics principles, emphasizing patient safety and well-being as paramount concerns. Responsible data sharing with third parties demands adherence to ethical principles, including privacy protection and informed consent. HIPs also bear ethical responsibilities towards their employers and the broader community, encompassing the protection of data and upholding professional standards. Ethical conduct must prioritize patient welfare and avoid harm, embodying the principles of beneficence and non-maleficence. Ultimately, responsibility and accountability for adhering to ethical principles rest squarely with the HIP and cannot be transferred to others. These key ethical principles serve as foundational pillars in guiding ethical decision-making and fostering responsible practice within the dynamic landscape of health informatics, upholding the trust and confidence of patients and society at large.

5. <u>Ethical Considerations in Research on Electronic Postings</u>

Delving into the realm of online environments where users generate postings poses complex ethical dilemmas, particularly regarding informed consent and privacy protection. These platforms, encompassing discussion lists, forums, social media, and networking sites, often host exchanges of medical information, raising significant ethical questions for researchers. One pivotal inquiry revolves around the treatment of electronic postings in terms of confidentiality and anonymity akin to patients in self-help groups. Resolving this issue hinges on the application of either the 'human subject' model or the 'textual object' model (Mattioli, 2014).

The human subject model extends medical ethics principles to electronic postings, viewing them as reflections of real individuals (Tiidenberg, 2018). Consequently, researchers must adhere to ethical standards regarding informed consent, privacy protection, and avoidance of harm to participants. Obtaining informed consent before referencing or quoting from such sites becomes imperative under this model.

In contrast, the textual object model contends that electronic postings are merely textual artifacts subject to standard laws and ethics governing text. Analogous to conversations in public spaces, postings on online platforms lack an expectation of privacy and confidentiality (Hannigan et al., 2019). This perspective challenges the necessity of informed consent unless personally identifiable information is disclosed. The absence of such information diminishes privacy concerns, especially if users have not taken measures to conceal their identities.

This model finds support in literary theory, which separates textual analysis from authorial intention or identity. It posits that discussions of text should be divorced from considerations of the author. Moreover, the textual object model aligns with legal definitions, particularly in the United States, where human subjects are defined as individuals from whom researchers obtain identifiable private information (Cohen, 2017). However, ethical considerations persist regarding the potential for harm or misuse of information, especially in contexts where corporate ownership of databases may lead to conflicts of interest. Researchers must remain vigilant in upholding ethical standards and ensuring that their work aligns with principles of beneficence and non-maleficence. By navigating these ethical complexities thoughtfully, researchers can contribute responsibly to the discourse surrounding online health information while safeguarding the rights and well-being of participants.

6. <u>Challenges and Considerations in Research on Electronic Postings</u>

Undertaking research on electronic postings presents unique challenges and ethical considerations, particularly in deciding between the application of the textual model or the human subject model (Sugiura et al., 2017). While the textual model may seem appealing due to its alignment with traditions from fields like sociology and literary theory, several issues arise when applying it to medically-related research in health informatics.

Firstly, the textual model overlooks the potential for aggregated data from multiple postings to inadvertently identify individuals, contrary to established medical ethics principles. Even if individual postings lack identifiable information, combining them can lead to privacy breaches and ethical concerns. Furthermore, relying solely on laws as a standard of ethics is problematic, as laws may only provide a minimum threshold rather than comprehensive ethical guidance (Wendel, 2005). This underscores the importance of health informatics researchers focusing on ethical guidelines tailored to their area of study.

On the other hand, using the human subject paradigm presents its own unique difficulties. Obtaining informed consent is challenging in large online groups with dynamic and fluctuating membership. Obtaining individual consent is impractical, if not impossible, due to the large number of participants. To address these challenges, researchers must carefully consider the level of privacy assumed within online communities and tailor their approach accordingly (Bietz et al., 2016). In instances where informed consent is unfeasible, researchers should refrain from referencing specific postings or individuals to preserve anonymity. Instead, aggregated data can be utilized to convey overall trends without compromising privacy. Moreover, researchers must exercise caution when introducing interventions or manipulations within online environments. The lack of informed consent in such scenarios can lead to ethical dilemmas, as demonstrated by the controversy surrounding the Facebook News Feed experiment conducted by Adam Kramer et al. Ethical research practices necessitate transparency, respect for privacy, and consideration of potential harm to participants (Cresswell et al., 2023).

In navigating these complexities, researchers must strike a delicate balance between scientific inquiry and ethical responsibility, ensuring that their methods uphold the principles of beneficence, non-maleficence, and respect for autonomy. By addressing these challenges thoughtfully, researchers can contribute responsibly to the advancement of knowledge in health informatics while safeguarding the rights and well-being of online participants.

7. Ethical Considerations and Professional Conduct for Medical Students in Health Informatics

In the realm of health informatics, medical students are entrusted with the responsibility of upholding ethical standards and professional conduct, reflecting their future roles as healthcare professionals. With the pervasive influence of digital technology, medical students must navigate complex ethical dilemmas and adhere to rigorous ethical guidelines (De Gagne et al., 2023). Particularly in the context of online professionalism and social media ethics, medical students must exercise caution when engaging in digital platforms. The blurring of boundaries between personal and professional lives necessitates careful consideration of the potential impact of online behavior on patient confidentiality and professional reputation. Consequently, medical schools are increasingly recognizing the importance of developing comprehensive social media policies to guide students in maintaining professionalism in digital spaces (Farnan et al., 2013).

In clinical settings, the use of mobile devices equipped with cameras introduces additional considerations regarding patient privacy and confidentiality. While these devices offer convenient access to medical information, medical students must be mindful of patient concerns regarding privacy and ensure that cameras are positioned in a manner that respects patient confidentiality. Moreover, engagement in research projects demands adherence to stringent ethical standards and academic integrity. Whether conducting independent investigations or collaborating on larger-scale studies, medical students must uphold honesty and integrity, seeking guidance from supervisors and ethics committees when faced with ethical dilemmas (Petersen et al., 2018).

Plagiarism and academic misconduct represent serious breaches of professional conduct that can have severe repercussions for medical students. Upholding honesty and integrity in scholarly endeavors is paramount, necessitating meticulous citation practices and the avoidance of unauthorized sources. Additionally, the ethical use of electronic files and resources entails respecting copyright laws and utilizing legitimate channels for accessing digital materials. While the temptation to access restricted materials via unauthorized means may arise, medical students must prioritize ethical conduct and explore lawful avenues for obtaining information (Petersen et al., 2018). Medical students are crucial in encouraging ethical norms and professionalism in health informatics. Medical students maintain the highest standards of professionalism by following ethical norms, using prudence in online activities, and conducting research with integrity and transparency. By integrating ethical principles into their professional identity, medical

students are prepared to ethically negotiate the complexity of health informatics, ensuring that their contributions have a positive impact on patient care and the healthcare industry as a whole (Crigger & Godfrey, 2014).

8. Conclusion

In conclusion, the landscape of health informatics ethics is characterized by its complexity and continuous evolution, shaped by the intersection of medicine, technology, culture, and law. As technological advancements continue to reshape healthcare delivery and patient experiences, the ethical considerations faced by health informatics professionals (HIPs) become increasingly nuanced and multifaceted. Despite efforts to establish comprehensive codes of ethics, navigating the ethical challenges posed by emerging technologies remains a formidable task for HIPs. Looking ahead, it is evident that health informatics ethics will confront new ethical dilemmas as digital medical data becomes more integral to patient care and healthcare systems. The ongoing tension between ethical principles, cultural norms, and legal frameworks further complicates decision-making in this field. However, HIPs, including students, must rely on fundamental ethical principles as guiding beacons amid these complexities, using their conscience to navigate ethical gray areas where existing frameworks may fall short.

Reflecting on the historical backdrop of medical ethics, which emerged from the atrocities of World War II, and the subsequent development of health informatics ethics, it is evident that ethical codes serve as foundational pillars for guiding ethical conduct in the digital age. While these codes may vary in effectiveness, they provide indispensable principles for medical students and health informatics professionals alike. As stewards of electronic data, it is imperative that individuals in these roles uphold these principles diligently, ensuring the ethical and responsible use of technology in healthcare delivery. In essence, the journey of health informatics ethics from its origins in the aftermath of Nuremberg to its current state underscores the importance of ethical awareness and conscientious practice in the field of health informatics. By embracing ethical principles and remaining vigilant in their application, HIPs can navigate the complexities of digital healthcare delivery with integrity and compassion, ultimately advancing the ethical practice of medicine in the modern era.

References

Berger-Walliser, G., & Scott, I. (2018). Redefining corporate social responsibility in an era of globalization and regulatory hardening. *American Business Law Journal*, 55(1), 167-218.

Bietz, M. J., Bloss, C. S., Calvert, S., Godino, J. G., Gregory, J., Claffey, M. P., ... & Patrick, K. (2016). Opportunities and challenges in the use of personal health data for health research. *Journal of the American Medical Informatics Association*, 23(e1), e42-e48.

Boyd, L. (2007). Ethical Conduct of Research in the Clinical Environment. *Canadian Journal of Medical Radiation Technology*, 38(2), 22-30.

Brody, H. (2014). The Origins and Impact of the Nuremberg Doctors' Trial. In *Human Subjects Research after the Holocaust* (pp. 163-173). Cham: Springer International Publishing.

Cohen, J. E. (2017). Examined lives: Informational privacy and the subject as object. In *Law and Society Approaches to Cyberspace* (pp. 473-538). Routledge.

Cresswell, K., Rigby, M., Magrabi, F., Scott, P., Brender, J., Craven, C. K., ... & Williams, R. (2023). The need to strengthen the evaluation of the impact of Artificial Intelligence-based decision support systems on healthcare provision. *Health policy*, *136*, 104889.

Crigger, N., & Godfrey, N. (2014). From the inside out: A new approach to teaching professional identity formation and professional ethics. *Journal of Professional Nursing*, *30*(5), 376-382.

De Gagne, J. C., Hwang, H., & Jung, D. (2023). Cyberethics in nursing education: Ethical implications of artificial intelligence. *Nursing Ethics*, 09697330231201901.

Detmer, D. E., Abner, T., & Greenwood, K. (2009). American Medical Informatics Association (AMIA). In *Encyclopedia of Library and Information Sciences* (pp. 88-89). CRC Press.

Du, S., & Xie, C. (2021). Paradoxes of artificial intelligence in consumer markets: Ethical challenges and opportunities. *Journal of Business Research*, *129*, 961-974.

Farnan, J. M., Snyder Sulmasy, L., Worster, B. K., Chaudhry, H. J., Rhyne, J. A., Arora, V. M., ... & Federation of State Medical Boards Special Committee on Ethics and Professionalism*. (2013). Online medical professionalism: patient and public relationships: policy statement from the American College of Physicians and the Federation of State Medical Boards. *Annals of internal medicine*, *158*(8), 620-627.

Gibson, C. J., Dixon, B. E., & Abrams, K. (2015). Convergent evolution of health information management and health informatics. *Applied clinical informatics*, 6(01), 163-184.

Hannigan, T. R., Haans, R. F., Vakili, K., Tchalian, H., Glaser, V. L., Wang, M. S., ... & Jennings, P. D. (2019). Topic modeling in management research: Rendering new theory from textual data. *Academy of Management Annals*, *13*(2), 586-632.

Hustinx, P. (2013). EU data protection law: The review of directive 95/46/EC and the proposed general data protection regulation. *University of Tartu. Data Protection Inspectorate, Tallinn*.

Kaliyah, Z. (2023). Teaching Ethics in the Age of AI: Strategies for Educators and Technologists. *Social Sciences Spectrum*, 2(1), 76-81.

Lai, A. M., Hsueh, P. Y., Choi, Y. K., & Austin, R. R. (2017). Present and future trends in consumer health informatics and patient-generated health data. *Yearbook of medical informatics*, *26*(01), 152-159.

Mattioli, M. (2014). Disclosing big data. Minn. L. Rev., 99, 535.

Moorthie, S., Hayat, S., Zhang, Y., Parkin, K., Philips, V., Bale, A., ... & Moore, A. (2022). Rapid systematic review to identify key barriers to access, linkage, and use of local authority administrative data for population health research, practice, and policy in the United Kingdom. *BMC Public Health*, 22(1), 1-13.

Petersen, C., Berner, E. S., Embi, P. J., Fultz Hollis, K., Goodman, K. W., Koppel, R., ... & Winkelstein, P. (2018). AMIA's code of professional and ethical conduct 2018. *Journal of the American Medical Informatics Association*, 25(11), 1579-1582.

Robson, G., Gibson, N., Thompson, A., Benatar, S., & Denburg, A. (2019). Global health ethics: critical reflections on the contours of an emerging field, 1977–2015. *BMC Medical Ethics*, 20(1), 1-10.

Schmidt, U. (2023). From Nuremberg to Helsinki: Historicizing the Codification of Post-War Research Ethics. In *Ethical Innovation for Global Health: Pandemic, Democracy and Ethics in Research* (pp. 149-174). Singapore: Springer Nature Singapore.

Sugiura, L., Wiles, R., & Pope, C. (2017). Ethical challenges in online research: Public/private perceptions. *Research Ethics*, *13*(3-4), 184-199.

Tiidenberg, K. (2018). Ethics in digital research. *The SAGE handbook of qualitative data collection*, 466-479.

Walpole, S., Taylor, P., & Banerjee, A. (2016). Health informatics in UK Medical Education: an online survey of current practice. *JRSM open*, 8(1), 2054270416682674.

Wendel, W. B. (2005). Legal ethics and the separation of law and morals. Cornell l. reV., 91, 67.