

Leveraging Data Ethics to Create Responsible Artificial Intelligence Solutions in Nursing: A Viewpoint

Patricia A. Ball Dunlap, Martin Michalowski

Submitted to: JMIR Nursing
on: May 28, 2024

Disclaimer: © The authors. All rights reserved. This is a privileged document currently under peer-review/community review. Authors have provided JMIR Publications with an exclusive license to publish this preprint on its website for review purposes only. While the final peer-reviewed paper may be licensed under a CC BY license on publication, at this stage authors and publisher expressly prohibit redistribution of this draft paper other than for review purposes.

Table of Contents

Original Manuscript.....	4
---------------------------------	----------

Preprint
JMIR Publications

Leveraging Data Ethics to Create Responsible Artificial Intelligence Solutions in Nursing: A Viewpoint

Patricia A. Ball Dunlap^{1, 2} MS, MSN, RN-NI, CPHIMS; Martin Michalowski¹ PhD, FAMIA

¹School of Nursing University of Minnesota Minneapolis US

²Center for Digital Health Mayo Clinic Rochester US

Corresponding Author:

Patricia A. Ball Dunlap MS, MSN, RN-NI, CPHIMS
School of Nursing
University of Minnesota
5-140 Weaver-Densford Hall
308 Harvard Street SE
Minneapolis
US

Abstract

AI ethics is gaining much recognition because of adverse outcomes or ethical concerns such as algorithmic bias, lack of transparency, trust, data security, and fairness. Interestingly, artificial intelligence technologies, specifically machine learning algorithms, are often the focal point for optimization and achieving ethical human-intelligent-like systems. However, these technologies are fueled by data. Data is hidden behind these complex systems and needs to come to the forefront regarding its ethical collection, processing, and use. Data ethics and its importance in attaining responsible artificial intelligence in healthcare and nursing via data ethical frameworks and strategies are introduced. Furthermore, the implications of data ethics for nurses are presented. A formal literature survey was employed to gather and analyze data from the perspectives of data ethical concepts and definitions, responsible artificial intelligence, and data-centric artificial intelligence in healthcare and nursing. Eight principles of data ethics are introduced for consideration. The data-centric artificial intelligence paradigm can support these principles via the ethical creation of artificial intelligence solutions that incorporate human-centered domain expertise to create high-quality, representative data. This engagement is essential in high-stakes healthcare settings to protect patients' data privacy and health outcomes. In conclusion, four recommendations are presented to nurse leaders, educators, and researchers to position and empower them to engage in data ethics in artificial intelligence to create ethical, high-quality, pertinent datasets from which machine learning algorithms can learn patterns and relationships embedded in the data.

(JMIR Preprints 28/05/2024:62678)

DOI: <https://doi.org/10.2196/preprints.62678>

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**

Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.

Only make the preprint title and abstract visible.

No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain visible to all users.

Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in a peer-reviewed journal, my article will be made fully visible to all users.

Original Manuscript

Abstract

AI ethics is gaining much recognition because of adverse outcomes or ethical concerns such as algorithmic bias, lack of transparency, trust, data security, and fairness. Interestingly, artificial intelligence technologies, specifically machine learning algorithms, are often the focal point for optimization and achieving ethical human-intelligent-like systems. However, these technologies are fueled by data. Data is hidden behind these complex systems and needs to come to the forefront regarding its ethical collection, processing, and use. Data ethics and its importance in attaining responsible artificial intelligence in healthcare and nursing via data ethical frameworks and strategies are introduced. Furthermore, the implications of data ethics for nurses are presented. A formal literature survey was employed to gather and analyze data from the perspectives of data ethical concepts and definitions, responsible artificial intelligence, and data-centric artificial intelligence in healthcare and nursing. Eight principles of data ethics are introduced for consideration. The data-centric artificial intelligence paradigm can support these principles via the ethical creation of artificial intelligence solutions that incorporate human-centered domain expertise to create high-quality, representative data. This engagement is essential in high-stakes healthcare settings to protect patients' data privacy and health outcomes. In conclusion, four recommendations are presented to nurse leaders, educators, and researchers to position and empower them to engage in data ethics in artificial intelligence to create ethical, high-quality, pertinent datasets from which machine learning algorithms can learn patterns and relationships embedded in the data.

KEYWORDS: artificial intelligence; data ethics; data-centric AI; nurses; nursing informatics; machine learning, responsible AI; data literacy; ai data ethics; dcai

Introduction

Artificial Intelligence (AI) has gained increasing popularity in the United States. News about AI's growing influence can be found in daily U.S. news; topics range from concerns about job replacement to AI's myriad and exciting applications in multiple industries. With vast electronic healthcare administrative and clinical data available for use, AI technology adoption and application are increasing in the healthcare sector - anticipated to increase by \$188 billion U.S. dollars by 2030, with annual growth rates between roughly 22% and 37% from the present until 2030.¹ Furthermore, AI ethics is gaining much recognition because of adverse outcomes or ethical concerns around algorithmic bias, lack of transparency, trust, data security, and fairness. A cursory review of content on an online global AI ethics case registry shows that AI incidents are expanding across multiple industry verticals.²

Interestingly, the machine learning algorithm or model is often the focal point in the headlines or journal article titles about ethical violations. For example, machine learning algorithms, including large language models (LLM), predict or generate incorrect or false medical results,³⁻⁵ biased AI models,^{5,6} and an algorithm contributing to health disparities because it failed to flag chronically ill African or Black American patients needing high-risk care management.^{5,7} These headlines and journal articles achieved their intended goal of getting readers' attention concerning a malfunctioned AI technology. However, upon further inspection, data begins to surface as the root cause for these algorithms' failures. Delving deeper into the AI technology's internal components will reveal that data is its foundation. Data fuels these impactful systems.⁸⁻

¹⁰ Using poor-quality, under-representative data to develop AI technologies has negative consequences, such as generative AI algorithms delivering erroneous responses (hallucinations) to their users and degraded machine learning model performance in production on unseen data. These issues can disrupt organizations' operations or public reputations, especially in incredibly high-stakes healthcare settings, because patient outcomes and safety are at risk. Data is hiding behind these complex AI systems and needs to come to the forefront regarding its ethical collection, processing, and use. Data ethics is essential for creating well-designed AI solutions and achieving responsible AI in healthcare, particularly nurse-specific AI technologies.

We introduce data ethics and its importance in attaining responsible AI in healthcare and nursing via

data ethical frameworks and strategies. These frameworks and strategies draw attention to AI data operations to attain high-quality datasets that may adequately train AI technologies to reach their intended goals. Furthermore, the implications of data ethics for nursing and nursing research will be discussed, and their significance in creating ethical, high-quality datasets for machine learning by promoting responsible AI in nursing.

Responsible AI

Responsible AI's goal is to ensure that AI systems are designed, developed, and deployed in a manner that is ethical, fair, transparent, accountable, and beneficial to all intended users (Zhang et al., 2023). It is multidimensional and strives to create standards and values that avoid issues concerning security, biases, and discrimination.¹¹ Data ethics is a facet of responsible AI from the perspective of data operations, such as the ethical collection, processing, and use of data. Getting data ethics wrong can have adverse outcomes, such as 57% of consumers mentioning they will discontinue patronizing businesses that have broken their trust when irresponsible data usage is revealed.¹² Additionally, leveraging suboptimal data to train machine learning algorithms can cause harm to patients, such as misdiagnosis,¹³ misidentification,^{13,14} or violation of their data privacy even if the data was deidentified before being used to train a machine learning algorithm.⁸

AI Data Ethics

What is Data Ethics?

Data ethics is the branch of ethics that studies and evaluates moral problems concerning data collection, generation, analysis, dissemination, sharing, and use, regardless of whether the data is unstructured or structured, including its varying modalities.^{12,15,16} Eight principles of AI data ethics⁸ are introduced and briefly described below:

1. **Transparency:** Is there clarity on the use and purpose of the collected data, including a clear understanding of its storage and protection?
2. **Fairness:** Is the data collection and its use fair, not exacerbating existing inequalities or biases?

3. **Privacy:** Does the data collection process and use respect individuals' privacy and autonomy? Informed consent can help achieve this.
4. **Responsibility:** Are data collectors and users held responsible for ensuring the data is collected and used ethically, including being held accountable for any harm resulting from the data collection and use? Are there mitigation steps in place?
5. **Security:** Is the data stored and transmitted securely to protect it from unauthorized access, use, or disclosure?
6. **Inclusivity:** Is there assurance that the data collected and used honors inclusivity and consideration of diverse perspectives and experiences, mainly underrepresented perspectives?
7. **Transparency in decision-making:** Are the decisions derived from the data explainable and interpretable?
8. **Continual assessment:** Does the organization continually monitor and assess its data collection and use practices, ensuring necessary adjustments align with the ethical principles?⁸

Ethical Data Frameworks

Multiple proposals for data ethical frameworks exist to support the above principles. Floridi et al. (2016) make a rational case for designing a macroethical data ethics framework.¹⁵ This notion means avoiding narrow, ad-hoc approaches so that organizations can create solutions that maximize the value of societal data science for everyone and their environments.¹⁵ Moreover, Marcovitch and Rancourt (2022) vouched for standardized tools that enable and integrate data ethics accountability mechanisms (i.e., disclosure and transparency processes) at the organizational level because countries can have varying legal frameworks.¹⁶ Their proposed standardized tools entail ethical components like integration of data ethics into the organization's culture, presence of data processes or management systems, a data governance structure, organizational disclosure and transparency when making ethical decisions concerning the data supply chain, and a consistent approach to demonstrating and verifying ethical data practices.¹⁶

As U.S. healthcare organizations continue to implement and integrate increasing AI technologies into administrative and clinical settings, the influence of and need for data ethics will expand. Organizations' reputations and revenues are at stake because of potential damage caused by suboptimal data used to develop AI technologies.¹⁶ For nursing research and practice, data ethics are pivotal in developing responsible AI technologies that affect nurses' care processes and workflows. These include protecting patients from algorithmic bias because of data partiality, protecting patient's sensitive data, and improving trust in the reliability of the data used to train the machine learning algorithm.

Data-Centric AI

Model-Centric Versus Data-Centric AI Paradigms

AI technologies leveraging machine learning are hungry for meaningful data. Machine learning is a sub-field of AI. It entails the computer's ability to learn and adapt with minimal to no human instruction via algorithms and statistical models. These systems require lots of data to learn underlying patterns and make their inferences or predictions. However, a model-centric strategy has been employed over the past decade to develop most current AI technologies. Instead of prioritizing data-related activities, the model-centric approach makes the machine learning algorithm or model the focal point for performance improvement.¹⁷ Data activities (i.e., curation, collection, labeling, etc.) take lower priority and are often a single occurrence. The ethical violations mentioned earlier are examples of the unfortunate effects this approach can cause (e.g., algorithmic bias, mispredictions, etc.).

The model-centric approach inadequately addresses the eight principles of data ethics. It overlooks the data's breadth, challenges, and fidelity as underlying problems in improving machine learning models' behaviors.¹⁸ Fortunately, the AI industry is becoming aware of the limitations of the model-centric AI strategy and, therefore, is beginning to focus more on the data (the fuel). The data as the focal point is at the heart of the data-centric AI strategy instead of the machine learning model.¹⁷⁻¹⁹ This approach centralizes data quality to achieve a high-performing machine learning model.^{9,18} Data activities are iterative, while the model optimization activities remain fixed.^{9,18} Data-centric AI distinctly encourages the engagement of domain expertise to attain relevant, high-quality datasets for machine learning.¹⁹

Data-Centric AI Role in Achieving Data Ethics & Responsible AI

The data-centric AI framework involves developing, iterating, and maintaining AI systems' data. It is concerned with building adequate training data, architecting proper inference data, and keeping the data for machine learning.¹⁸ Considering the significance of high-quality data, data-centric AI aligns with many principles of data ethics and responsible AI. For example, careful curation and collection of data uphold fairness, responsibility, and transparency ethical principles. The engagement of domain expertise achieves inclusivity, transparency in decision-making, and privacy. Domain experts can include clinicians, clinical informaticists, and regulatory and privacy specialists. These diverse perspectives can play a critical part in protecting patient data privacy and ensuring substandard data does not cause patient harm. The perception of data as a notable product, separate from the machine learning model, encourages establishing continual assessment guidelines of the healthcare organization's data collection and use practices.

Significance of Data-Centric AI and AI Data Ethics in Nursing

AI is emerging in nursing research and practice. A recent scoping review mentioned various activities and applications of AI in nursing.²⁰ Nurse researchers and informaticists must recognize the differences between model-centric and data-centric AI²¹ and their effects on achieving safe and effective AI technologies in healthcare settings that affect their care process and workflows. Furthermore, increasing awareness about principles of data ethics and their role in achieving responsible AI in healthcare is equally important. Nurses can engage with data scientists, engineers, and other AI specialists in data-centric AI activities to produce meaningful, high-quality data and datasets that lead to high-performance machine learning models fitting for nursing clinical and administrative workflows.²¹ Moreover, nurses offer valuable perspectives on patient safety and privacy and understand nursing data collection at the points of care; hence, they can make valuable contributions to help healthcare organizations achieve the principles of AI data ethics.

Conclusion

Working with data is a time-consuming and challenging affair. It is often perceived as less exciting than developing a machine learning model or AI technology. With all the buzz surrounding generative AI and large language models like ChatGPT, one can see this in everyday life. Data is the

foundation of these AI systems and is vital to achieving high-performing AI technologies in healthcare via the data-centric AI strategy. Data ethics promotes responsible AI and is essential to creating ethical AI technologies that can learn from meaningful, high-quality data.⁸ Methods employed to collect, store, use, and share data have significant implications for individuals, organizations, and society.⁸ To conclude, four recommendations are presented to create a path forward for nurses in various roles to participate in and contribute to creating responsible AI technologies that align with their workflows and adhere to the principles of data ethics.

Nursing Practice and Research Implications

Machine learning algorithms, including generative AI algorithms, trained on poor-quality and unrepresentative datasets have political consequences in healthcare, exacerbating bias and health disparities and compromising patient safety and privacy. Leveraging nurses' domain expertise and unique perspectives in data ethics and data-centric AI processes can confront the political consequences of poorly designed AI technologies by creating responsible technologies that place ethical, high-quality, and relevant data as a significant driver.

Recommendations for Nursing

Recommendation 1: Data Ethics Engagement Necessitates Data Literacy in AI

AI is anticipated to become more ingrained into the day-to-day activities of nurses in various clinical and administrative settings and research. Nurse leadership should seek to increase nurses' data literacy in the context of AI at the organizational level down to the individual team level. Nurse educators and researchers should seek to elevate their data literacy proficiencies and pass this valuable knowledge on to nursing students, especially those enrolled in nurse informatics degree programs or with nurse informatics research interests. Data literacy is the ability to effectively explore, read, write, understand, and communicate data meaningfully in a given context.^{22,23} Improved AI & data literacy among nurses can increase their awareness and knowledge about how they produce and consume health data leveraged by AI technologies.

Moreover, improved data literacy promotes conversations about data used in AI. These conversations start the genesis of establishing a common language that delineates what data literacy means in the context of nursing AI. Having a common language and foundational data knowledge prepares and empowers nurses to become data stewards, engage in conversations about data ethics, innovate ways to manage and harness their data, and work alongside technical AI specialists to create nurse-specific AI technologies responsibly. Nurses engaging in data conversations and collaborating with technical AI specialists align well with the inclusivity and responsibility principles of data ethics.

Recommendation 2: Data-Oriented Culture Motivates Ethical Accountability Mechanisms

Creating and nurturing a data-oriented culture among nurses can increase participation in AI data ethics accountability mechanisms, as outlined by Marcovitch and Rancourt (2022), in clinical and administrative settings. A data governance structure should exist for organizations having a data-oriented culture. Nurse leadership and researchers should seek to bring more data awareness and context to nurses so that they understand how they fit into the overall big-data picture. Various nursing roles can contribute to creating standardized data accountability instruments and processes that can effectively evaluate and measure AI data ethics, especially for nurse-specific AI technologies. Furthermore, nurse scientists should explore novel approaches, frameworks, and instruments that enable and integrate accountability mechanisms and effectively assess the principles of AI data ethics to achieve responsible AI supported by scientific evidence. Generating standardized data accountability mechanisms helps nurses and the healthcare organization achieve all eight data ethics principles.

Recommendation 3: Optimal Data Quality Is Conditioned on Domain Expertise Participation

Domain expertise is essential to creating high-quality data,²¹ and human involvement is crucial to successfully executing data-centric AI tasks.¹⁸ Leveraging their knowledge about data-centric AI and data ethics, nurses should seek to engage their domain expertise to affect end-to-end data-centric AI development activities positively. Their engagement can attain high-quality data and datasets that achieve ethical and safe AI solutions. For example, there are opportunities for nurses, especially nurse informaticists, to participate in data operations and processes. During the AI lifecycle development, nurses can help identify

and resolve opaque data decisions that could impact front-line clinicians' use and trust of AI technology (transparency in decision-making principle). This active participation also ensures patient data privacy (privacy principle). Additionally, nurses' active involvement in data-centric AI activities, including developing their data culture, promotes data ownership that will steer nurse-specific AI technologies.

Recommendation 4: High-Quality, Ethical Data Curtails Healthcare Political Consequences

Lastly, nurse leaders, educators, and researchers should be cognizant that implementing responsible AI technologies and initiatives in healthcare is not straightforward and often challenging despite the heightened interest in general AI ethics.⁵ High-stakes healthcare settings have unique concerns, such as patient privacy and safety, federal and local regulatory requirements, many clinical care processes, etc. This statement is not intended to dissuade nurses from taking on the challenge of uncovering methods to create ethical AI technologies that leverage ethical, high-quality, and representative data. Instead, to bring awareness and motivate nurses to push through the challenges because AI technologies are said to be politically designed, imbued with their designers' value choices, beliefs, and norms, including the data and datasets used to train them.^{5,24} As stated earlier, data is fuel, the foundation powering AI technologies. Data can have political consequences when considering its operations, such as selection, labeling, pre-processing, and transformation.²⁴ The operations lead to features or attributes in a dataset that a machine learning algorithm can learn data patterns and relationships, posing risks such as algorithmic bias.²⁵ Nurses operate at various touchpoints in the healthcare ecosystem in myriad settings. This knowledge base brings new perspectives that can curtail algorithmic political consequences by promoting the inclusivity principle of data ethics.

References

1. Stewart C. Artificial intelligence (AI) in healthcare market size worldwide from 2021 to 2030. September 28, 2023. Accessed December 2, 2023. <https://www.statista.com/statistics/1334826/ai-in-healthcare-market-size-worldwide/>
2. AI Ethicist. AI ethics case studies & AI incident registries. Accessed December 28, 2023, <https://www.aiethicist.org/ethics-cases-registries>
3. Bhattacharyya M, Miller VM, Bhattacharyya D, Miller LE. High rates of fabricated and inaccurate references in ChatGPT-generated medical content. *Cureus* 2023;15(5):e39238. doi:10.7759/cureus.39238
4. Emsley R. ChatGPT: these are not hallucinations – they're fabrications and falsifications. *Schizophrenia*. 2023;9(1):52. doi:10.1038/s41537-023-00379-4
5. Siala H, Wang Y. SHIFTing artificial intelligence to be responsible in healthcare: a systematic review. *Social Science & Medicine*. 2022;296:N.PAG-N.PAG. doi:10.1016/j.socscimed.2022.114782
6. Mittermaier M, Raza MM, Kvedar JC. Bias in AI-based models for medical applications: challenges and mitigation strategies. *NPJ Digit Med* 2023;6(1):113. doi:10.1038/s41746-023-00858-z
7. Obermeyer Z, Powers B, Vogeli C, Mullainathan S. Dissecting racial bias in an algorithm used to manage the health of populations. *Science* 2019;366(6464):447-453. doi:10.1126/science.aax2342
8. Anthony JR. Ethical Use of Data in AI Applications. In: Miroslav R, ed. *Ethics - Scientific Research, Ethical Issues, Artificial Intelligence and Education*. 1st edition. IntechOpen; 2023:chap 9. ISBN: 9781837695256
9. Budach L, Feuerpfeil M, Ihde N, et al. The effects of data quality on machine learning performance. *arXiv*. 2022; doi: 10.48550/arXiv.2207.14529
10. Ng A. A chat with andrew on mlops: from model-centric to data-centric ai. March 24, 2021. Accessed October 8, 2022. <https://www.youtube.com/watch?v=06-AZXmwHjo>
11. Merhi MI. An assessment of the barriers impacting responsible artificial intelligence. *Information Systems Frontiers* 2023;25(3):1147-1160. doi:10.1007/s10796-022-10276-3
12. Cognizant. Data ethics: what is data ethics? Cognizant. Accessed November 18, 2023, <https://www.cognizant.com/us/en/glossary/data-ethics>
13. Roberts M, Driggs D, Thorpe M, et al. Common pitfalls and recommendations for using machine learning to detect and prognosticate for COVID-19 using chest radiographs and CT scans. *Nature Machine Intelligence* 2021;3(3):199-217. doi:10.1038/s42256-021-00307-0
14. Heaven WD. Hundreds of AI tools have been built to catch covid. None of them helped. July 20, 2021. Accessed December 2, 2023. <https://www.technologyreview.com/2021/07/30/1030329/machine-learning-ai-failed-covid-hospital-diagnosis-pandemic/>
15. Floridi L, Taddeo M. What is data ethics? *Philosophical transactions* 2016;374(2083):20160360. doi:10.1098/rsta.2016.0360
16. Marcovitch I, Rancourt E. A data ethics framework for responsible responsive organizations in the digital world. *Statistical Journal of the IAOS* 2022;38:1161-1172. doi:10.3233/SJI-220067
17. Hamid OH. From model-centric to data-centric AI: A paradigm shift or rather a complementary approach? Paper presented at: 2022 8th International Conference on Information Technology Trends (ITT); May 25-26, 2022; Dubai, United Arab Emirates. Accessed October 8, 2022. doi:10.1109/ITT56123.2022.9863935
18. Zha D, Bhat ZP, Lai K-H, et al. Data-centric artificial intelligence: a survey. *arXiv*. 2023;doi:10.48550/arXiv.2303.10158
19. Artificial Intelligence Board of America. Data-centric AI vs. model-centric AI - everything you

need know. September 23, 2022. Accessed December 14, 2022. <https://www.artiba.org/blog/data-centric-ai-vs-model-centric-ai-everything-you-need-know>

20. Hwang GJ, Chang PY, Tseng WY, Chou CA, Wu CH, Tu YF. Research trends in artificial intelligence-associated nursing activities based on a review of academic studies published from 2001 to 2020. *Comput Inform Nurs* 2022;40(12):814-824. doi:10.1097/CIN.0000000000000897

21. Ball Dunlap PA, Nahm ES, Umberfield EE. Data-Centric Machine Learning in Nursing: A Concept Clarification. *Comput Inform Nurs* 2024;42(5) doi:10.1097/CIN.0000000000001102

22. Panetta K. A Data and analytics leader's guide to data literacy. Gartner.com. August 26, 2021. Accessed January 13, 2024. <https://www.gartner.com/smarterwithgartner/a-data-and-analytics-leaders-guide-to-data-literacy#:~:text=What%20is%20data%20literacy%3F,case%2C%20application%20and%20resulting%20value.>

23. Stobierski T. Data literacy: an introduction for business. Harvard Business School Online. February 23, 2021. Accessed 1/13/2024. <https://online.hbs.edu/blog/post/data-literacy>

24. Faraj S, Pachidi S, Sayegh K. Working and organizing in the age of the learning algorithm. *Information and Organization* 2018;28(1):62-70. doi:10.1016/j.infoandorg.2018.02.005

25. O'Connor S, Booth RG. Algorithmic bias in health care: opportunities for nurses to improve equality in the age of artificial intelligence. *Nurs Outlook* 2022;70(6):780-782. doi:10.1016/j.outlook.2022.09.003