

Use of Machine Learning for Personalized Care for Persons with Disabilities: Ethical and Privacy Issues

Guillermo V. Red Jr^{*1}, Thelma D. Palaoag²

Submitted: 07/02/2024 Revised: 15/03/2024 Accepted: 21/03/2024

Abstract: Machine learning remains the future of care personalization, especially in caring for persons with disabilities. However, critical ethical and privacy challenges arise, which potentially derail the deployment of machine learning technologies. This research has explored these challenges, considered possibility of machine learning being used to resolve the challenges, and examined the policy and governance frameworks that could be used to address the problem. The study adopted a scoping review method, where a scoping review process was conducted for each of the three research questions. This approach made it possible to offer an in-depth assessment of all aspects of the research problem. The findings support the available literature by establishing that critical privacy and ethical challenges exist. These challenges fall under three main categories: the technology, practice, and data. Like any other technology, machine learning is vulnerable to malicious activity and its use could breach patient privacy. Since it involves handling patient data, there is a possibility that the handling of the data itself poses privacy and ethical risks.

Keywords: Artificial Intelligence, Big Data, Data Analytics, Data Privacy, Machine Learning

1. Introduction

Care personalization is a major concern in healthcare. Practitioners strive to find the best mechanisms, tools, and frameworks that can ensure that care is tailored to the specific needs of the patients. More often, new and novel technologies present the best solutions to this problem. Therefore, it is not a surprise that healthcare institutions globally are undergoing digital transformation. Most notably, there is a growing use of software and Internet of Things (IoT) services. The emergence and rise of artificial intelligence (AI) and related technologies, especially machine learning, offer a new perspective to care personalization efforts.

People with disabilities are often neglected in healthcare and other contexts. Today, institutions and regulatory bodies are pushing for a more inclusive healthcare service provision. According to Namoun et al.[22], people with disabilities or special needs comprise 15% of the global population. Of these, over 466 million suffer from hearing problems, while 75 need access to wheelchairs. The diversity of disability poses a major challenge in healthcare. For instance, the disabilities may be physical, cognitive, or sensory impairments. This diversity means it is impossible to design standard care practices or solutions that cover all needs. Care personalization also goes beyond the broader classification of disability. This is because even individuals with similar disabilities will require different care plans.

Machine learning provides the desired capabilities to make care personalization a possibility. However, new technologies continually raise ethical and privacy challenges, especially where sensitive personal data is involved. In other cases, the interaction between new technologies and patients presents ethical challenges. The focus of this research is to explore the ethical and privacy issues in using machine learning in care personalization that are specific to people with disabilities. The research answers the following study questions:

- What are the ethical and privacy challenges of using machine learning for personalizing care for people with disabilities?
- Can machine learning help address ethical and privacy issues in care personalization efforts targeting people with disabilities?
- What are the available policy and governance frameworks for addressing the challenges?

2. Literature Review

2.1. Machine Learning in Care Personalization

Current literature offers a vivid view of how smart technologies are revolutionizing healthcare. The smart technologies are founded on AI, which can be described as machines working intelligently. Among the key types of AI is machine learning, which provides machines the ability to learn without explicit programming to facilitate such learning. According to Domingo[6], machine learning leverages advances in such areas as speech recognition, computer vision, and auditory scene analysis to interpret data and inform decision-making. In care personalization for the

¹ Computer Studies Department, Bicol University Polangui 4506, Albay Region V, Philippines

² College of Information Technology and Computer Science, University of the Cordilleras, Baguio City, CAR, Philippines

* Corresponding Author Email: gjvred@bicol-u.edu.ph

disabled patients, such capabilities are essential in designing solutions to health problems or designing custom care plans for the patients.

Personalized care is an emerging paradigm in healthcare where interventions are designed based on individual patient requirements and characterized as opposed to the standard or the “one-size-fits-all” approach. The new paradigm requires new and powerful methods to help make sense of the massive data[13]. The rationale is that care personalization is a data-driven practice, which implies that big data is in play[27]. Handling big data presents a challenge for any practice, hence the growing role of AI and machine learning. There is adequate literature to suggest that big data and big data analytics forms the backbone of care personalization[3]. The same literature acknowledges that big data analytics is achieved with the help of complex and advanced technologies involving AI and machine learning[17]. Therefore, machine learning is an inalienable aspect of the care personalization paradigm without which big data would become less useful.

It is important to emphasize that the primary role of machine learning lies with its predictive capabilities. Currently, many studies on the use of machine learning in health focus on this predictive function and illustrate how accurately machine learning predicts health outcomes, prognostics, diagnosis, and designing of care plans[30]. Machine learning used algorithms, for instance, Bayesian and neural networks, and data mining algorithms, for example, classification and clustering, alongside various decision-support and recommendation systems to generate predictive models[29]. Across all its applications, machine learning uses its ability to process natural language to analyze massive volumes of data to generate actionable insights from big data.

A key point for emphasis is that in care personalization, machine learning goes beyond predictive applications. Another key role in this regard is assistive applications, often designed for patients with disabilities. For example, machine learning is used in design and development of automatic speech recognition for patients with speech impairments[18]. The possibilities offered by assistive technologies are the main reason behind the global rise in demand for these technologies. The rise in demand raises new problems, including the challenge by practitioners to determine the best assistive technologies for the different patients[7]. In this regard, machine learning is also helpful in personalizing assistive technology choices due to the analytic capabilities.

2.2. Ethics and Data Privacy in Care Personalization

Big data and big data analytics are at the heart of care personalization. Across most practices, handling information raises major ethical and privacy concerns. It can be expected that care personalization for people with

disability faces the same challenge with or without deploying machine learning and related technologies. However, most ethical and privacy challenges emerge at the intersection between data and technology. Personalizing care exposes the sharp juxtaposition between different and yet complementary moral principles: optimizing care and complex data-handling technologies[16]. Success in care personalization depends on how the two moral principles are balanced. In other words, handling medical and personal data for use in care personalization must be done in consideration of the risk, ethics, confidentiality, trust, and privacy attached to the data. Current literature illustrates that personalized care cannot be complete without properly addressing data privacy. The matter of data privacy is deemed complex and inalienable from the broader social phenomenon of privacy of individuals’ lives[4]. This literature highlights the need to pursue the ethical and privacy discourses in care personalization.

Care personalization raises ethical concerns across several fronts. First, care personalization is backed by data obtained from research, which raises issues of informed consent, data protection, confidentiality, and the right of people to know or not know. In other words, research in personalized care must be conducted ethically[23]. Second, using the data for predictive purposes may raise ethical issues associated with discrimination. The rationale is that individuals responding to drugs or research parameters in certain ways could be discriminated against. People’s predispositions could be captured in the data to produce biased predictions. Such biased predictions discriminate against such individuals in care planning and delivery. Lastly, research conducted for care personalization may significantly raise the costs of care, which is considered unethical. In this case, healthcare providers are considered to have an ethical obligation to ensure that care is accessible.

Personalized care requires integrating biomedical and social data into research to establish how people’s social and physical environments, behaviors, and genetic endowments influence their health. Current literature suggests that all this data is used to design custom therapeutic and preventive interventions targeting the characteristics of each patient. The main challenge is that such data can cover a wide range of data forms, including diagnoses by physicians and simple metrics regarding an individual, for example, weight[5]. Such data can be massive, but the major risk arises because many medical institutions can access the data. Additionally, the data is not collected exclusively within the medical context. On the contrary, some of the data can be derived from external sources, including online platforms, the Internet, and apps [24]. Data from external sources could be highly personal and sensitive, which explains why its use raises ethical concerns. In other cases, such data is considered private, and its access and use potentially breaches privacy rules. Today, healthcare institutions must

consider the implications of the General Data Protection Regulation (GDPR) and other international and national data regulations[2]. Even when the data is critical in care personalization, institutions could still face legal consequences in the process of accessing and using the data.

2.3. Ethical and Privacy Concerns of Machine Learning in Healthcare

Like all technologies used in healthcare, there is considerable literature on the ethical and privacy problems machine learning faces in healthcare. However, this literature is significantly broad as it includes the broader AI and practice fields in healthcare. In this case, the literature acknowledges that machine learning is critical to the digitization of healthcare data with wide applications in prognosis, diagnosis, personalized treatment, clinical decision support, biomedicine, and drug development[1]. Across these applications, institutions must consider the ethical and privacy implications involved in managing healthcare data using machine learning algorithms. Most importantly, governments have implemented legislation governing fairness, privacy, transparency, accountability, and conflict of interest in designing and deploying machine learning algorithms and applications in healthcare[1]. Scholars acknowledge that the laws are not adequate because, despite efforts by institutions, clinical data can still be hacked for malicious purposes[8]. Therefore, even the safe use of clinical data does not guarantee the privacy and security of the data.

Machine learning and other AI-related technologies are vital in disseminating health data. Machine learning helps gather data from various sources, including social media, online platforms, and wearable devices. This data can be unlawfully accessed by external users, especially biotechnology and pharmaceutical firms, for use in the development of new drugs and medical products. Other testing and bioinformatics deliberately sell the data, especially involving genetics, to pharmaceuticals, thereby breaching privacy and confidentiality rules[8]. The fact that such data is made available by machine learning applications links these tools to the ethical and privacy problems involving the use of such data. Essentially, using machine learning with such systems as deep learning and artificial neural networks touches on fundamental normative concepts, including trustworthiness, agency, responsibility, and transparency[11]. Additionally, machine learning could also be associated with evidentiary problems arising from biased or erroneous analysis of data, leading to inscrutable, inconclusive, or misguided evidence. The main consequence is that such output could be used for decision-support, leading to errors in healthcare practices. In other words, ethical and privacy issues of machine learning in healthcare go beyond the handling and management of healthcare data.

2.4. Assessing Gaps in Literature

The current research examines machine learning applications in care personalization for people with disabilities and the ethical and privacy issues involved. The available literature is rather broad and hardly focused on this specific issue. Therefore, there is a massive gap in the literature that must be filled by narrowing down the context of the research. However, it is important to acknowledge recent efforts in addressing the research problem. A few have addressed the ethical and privacy implications of the broader AI technologies in caring for disabled individuals. For example, a study by Wangmo et al.[28] suggests that scholars and practitioners agree that there are promises and challenges involved in AI in caring for age-related disabilities, but there are inadequate efforts to examine how the challenges can be resolved. Another study by Lillywhite and Wolbring[15] emphasizes that disabled people are the most likely users of scientific and technological products and processes involving AI and machine learning. Such uses attract many ethical issues, which indicates the need for a discourse on ethics and its relationship with AI and machine learning in caring for disabled people. These studies indicate that there have been at least some efforts to address the problem.

Splitting the topic into ethics and privacy yields better results. Regarding ethics, some studies explore machine learning from a fairness and social justice approach by exploring how the technology facilitates achieving justice for people with disabilities[10]. Other studies, even though focusing on the broader AI technologies, perceive these technologies as a means to ensure disability inclusion, but the use of the technologies is unethical for various reasons [27]. In other cases, ethical issues arise from stakeholder values and presences regarding privacy, disability, and identity[14]. The same trend can be observed regarding the separate topic of privacy, where it is apparent that some studies have raised questions regarding privacy concerns in using machine learning for care personalization for people with disabilities. These examples do not indicate an exhaustive and conclusive literature on the subject. On the contrary, they illustrate how shallowly the topic has been examined. Therefore, it can be concluded that there is a massive research gap in the field of ethics and privacy challenges specific to care personalization for disabled individuals using machine learning.

3. Methodology

3.1. Qualitative Research

This study adopts a qualitative approach, which entails collecting and analyzing non-numerical data. The data often comes in the form of video, text, or audio and often helps understand experiences, concepts, and opinions. In this case, the qualitative approach is used to assess textual data

obtained from recent scholarly sources, addressing the three research questions that form the backbone of this research. The nature of qualitative research makes it the perfect choice for this research. In essence, qualitative studies comprise a type of research designed for exploring and providing deeper insights into real-world problems. In contrast to quantitative studies that seek to collect numerical data points, introduce treatments, or intervene in a problem, qualitative research helps generate hypotheses and offers further investigation and understanding of quantitative data[26]. Therefore, qualitative approaches do not necessarily have to compete against quantitative studies because the former can complement the latter to help make even more sense of the quantitative data.

Qualitative research encompasses multiple methods of data collection and analysis. At its core, qualitative research asks open-ended questions whose responses cannot easily be classified into numbers. This means that qualitative studies are often non-linear, like quantitative designs. The greatest strength of qualitative studies desired for this research is the ability to explain patterns and processes. However, it is important to emphasize that this research uses secondary data with the aim of assessing the ethical and privacy issues in machine learning use in care personalization for disabled patients. Therefore, the patterns and processes are not a major priority in this research.

3.2. Systematic Scoping Review

A scoping review is the study design adopted in this study. Scoping studies can be described as a further type of literature review because it seeks to map the body of literature on a topic. This can be contrasted with a systematic review, whose focus is on summarizing the best available research on a specified question. The scoping review can also identify gaps in the literature and could be a step before conducting further research or another type of research. Essentially, the analysis of research gaps presented in the literature reveals that the research topic has been largely neglected in recent literature. Therefore, a scoping review is considered the best design because further research would be necessary to fill the gaps. In this case, a different type of research may be the best step to take, especially since primary data would be critical in filling the identified gaps. The scoping review will help assess the current state of the literature and pave the way for further inquiry into the topic.

3.3. Data Collection and Analysis in a Scoping Review

A scoping review comprises five steps and a PRISMA flow chart. The five steps include identifying the research question, identifying studies, selecting studies, charting the data, and summarizing and reporting the findings. Figure 1 below illustrates the PRISMA flow diagram for a scoping review process:

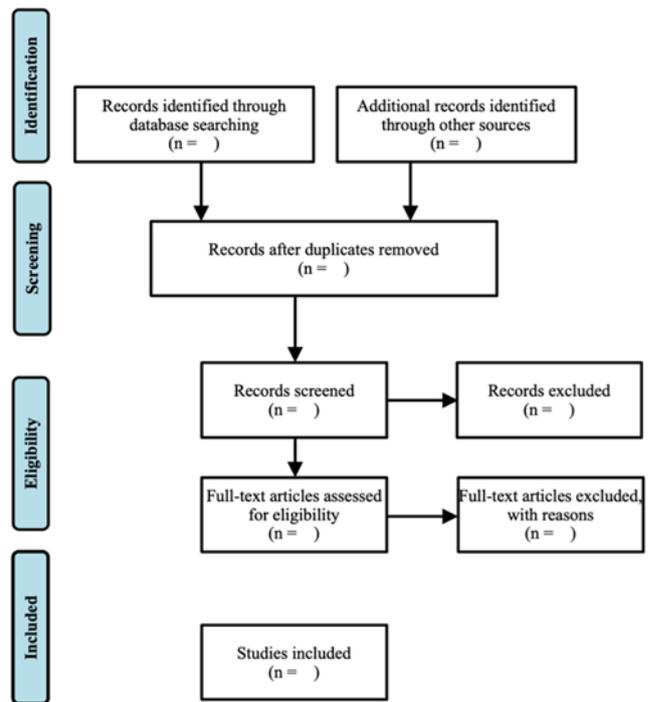


Fig. 1. A PRISMA flow diagram for a scoping review process[22].

The research questions have already been identified. Therefore, the next steps in the collection and analysis of data should be identifying relevant studies and selecting among them those that best serve the purpose. Selecting studies involves designing search keywords to be used across the selected databases. In this case, health-related journals and databased would be preferred, including Embase, NCBI, and Medline. However, studies on machine learning have a scope wider than the healthcare context. Therefore, more generalized databases would also be searched, including MDPI, JAMA, ResearchGate, Springer, Elsevier, and Sage Open. The record obtained from Google Scholar will also be critical.

The search results from the selected databases and other sources are recorded, before the initial screening process starts. The screening process comprises an inclusion and exclusion criteria used to select the studies. The criteria includes relevance, currency, and credibility. To achieve the criteria, all sources must be scholarly and published within the last 5 years. After screening, the resulting number of studies is also recorded, as well as the number of excluded studies. Further screening for eligibility is conducted, this time focusing on the full text of the articles. In this case, the content must be relevant in that it addresses the research questions. After this screening, the number of included and excluded studies is also recorded as indicated in the PRISMA flow chart. The final selection of included studies is used for summarizing and reporting the data. In this study, a summary of the findings will be tabulated followed by a narrative synthesis that explains the findings. It is important to emphasize that the three research questions are separate

and require a different set of resources. Therefore, a separate scoping review will be conducted for each of the research questions. This means repeating the entire process from the identification of the research question to the summary and reporting of the findings.

4. Results and Discussion

Each of the three research questions is subjected to a separate scoping review. Figures 2 to 4 illustrate the scoping process for the three research questions in the order in which they are presented in the introduction.

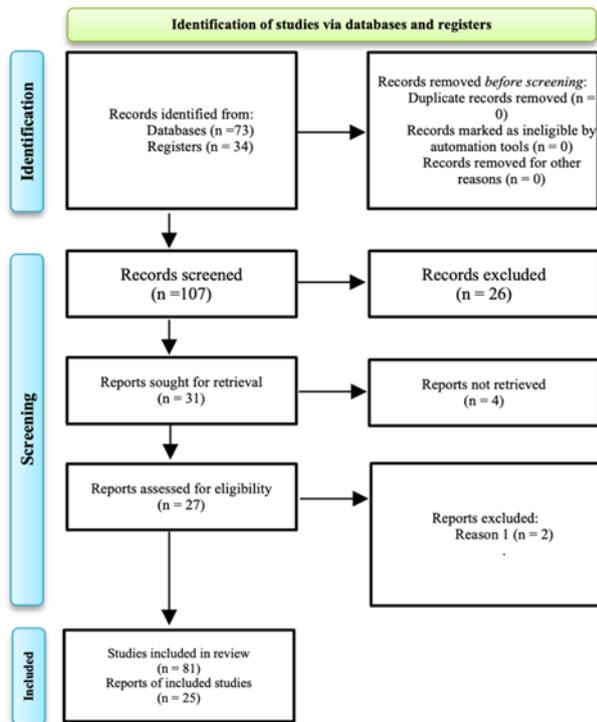


Fig. 2. PRISMA flow chart for the first research question

For the first research questions, the initial search from databases and registers yielded 107 studies and 31 reports. After screening, the number of included studies and reports were 81 and 25 respectively. It is important to point out that the primary reason for report exclusion was the lack of adequate bibliographical data, making the reports lose their credibility.

A total of 38 studies on the second research question were obtained during the initial search from databases and registers, while 12 reports were obtained. Screening reduced these figures to 32 and 8 for studies and reports, respectively. The reason that the one report was excluded was inadequate information on the subject.

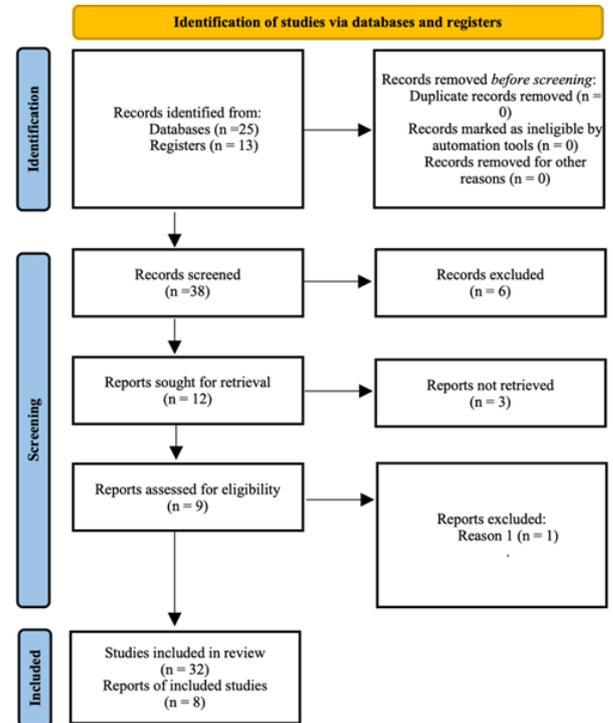


Fig. 3. PRISMA flow chart for the second research question

For figure 4, A total of 51 studies on the second research question were obtained during the initial search from databases and registers, while 23 reports were obtained. Screening reduced these figures to 47 and 14 for studies and reports, respectively. The four reports were excluded because they deviated from the subject matter of the research.

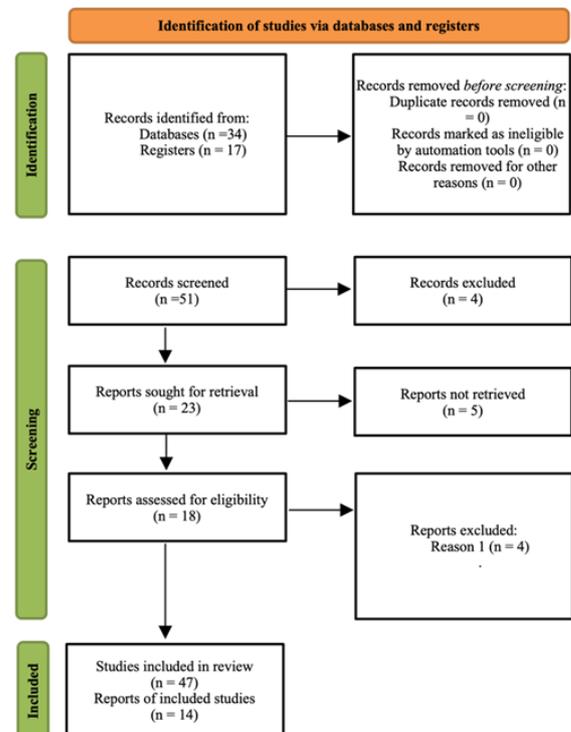


Fig. 4. PRISMA flow chart for the third research question

Taken together, the scoping review yielded a significant number of materials that are classified as studies and reports. In this case, the studies describe those sources comprising scientific and empirical research that are peer-reviewed and published on the various journals. The main inclusion and exclusion criteria used in the screening process for the studies included the sources being published within the last five years, peer-reviewed, published in reputable journals, and containing the relevant information. Reports comprised other documents published for purposes other than research, including government, non-government organizations, hospitals, and even industry reports.

4.1. Ethical and Privacy Challenges of Machine Learning in Care Personalization for Disabled Patient

Even with the scant literature on the subject, the study managed to find considerable amount of information regarding ethical and privacy issues arising from the use of machine learning in care personalization for disabled patients. The sources gathered to answer this question were varied in terms of their primary focus and the extent to which they addressed the question. It is important to acknowledge that over 87% of the sources generalized AI in care personalization with adequate mentions and references to machine learning. The rest either specified machine learning or explored research topics that included machine learning and its use in care personalization for disabled patients. However, it must be acknowledged that there is an extreme scarcity of sources that combine machine learning, care personalization, disabled patients, and ethical and privacy challenges in one study.

The findings, as summarized in Table 1, classify the ethical and privacy challenges based on the various dimensions or areas affected. These include challenges with the technology itself, challenges with the data, and practice challenges.

Table 1. Summary of ethical and privacy challenges in machine learning

	Privacy Challenges	Ethical Challenges
Technology	Patient monitoring Surveillance Links with IoTs	Biased decisions Consent Algorithmic transparency Patient autonomy
Practice	Patient confidentiality Intrusion of privacy	Lack of human control Failure to check output

	Documentation	Overreliance on the technology
Data	Leaking sensitive information Unauthorized data access	Violations of privacy Data sharing

Care personalization for disabled patients is sensitive because of the ethical and privacy challenges involved. The main rationale for classifying the findings into technology, practice, and data is that the three areas have different ethical and privacy implications. In other words, the challenges can emanate from the technology itself, the practice, or data. Technology-related challenge focus on how machine learning, as a healthcare technology, affects ethical practice and privacy. The study found that machine learning can breach personal privacy when used for monitoring surveilling patients, or when linked with other IoTs used in healthcare. Ethical problems facing the technology includes the possibility of making biased decisions, lack of patient consent and autonomy, and problems with algorithmic challenges. In terms of practice, the health care practitioners can conduct themselves in a manner that affects privacy and raises ethical concerns, including how they use machine learning technologies. The main challenges in this regard include intrusion of privacy, documentation, and patient confidentiality. Data issues include breaches and leakage of sensitive patient information, violations of data privacy, and data sharing challenges.

4.2. Can machine learning help address ethical and privacy issues in care personalization efforts targeting people with disabilities?

Researching the second study question was more complex than the others. The main reason is that there is hardly any literature directly addressing the question. Therefore, over 98% of the sources found were only sufficient for making inferences. In other words, the exclusion and inclusion criteria used to screen sources had to be changed to make it possible to find sources. The change included expanding the scope of the search to include general topics. The keywords were simplified to search for any evidence that machine learning could be used as a tool to address ethical and privacy issues in healthcare. The strategy was successful, and the research established that there are strategies that can make machine learning useful in dealing with privacy and ethical challenges. A summary of the findings is presented in Table 2 below:

Table 2. Summary of findings for the second research question

Source Citation	Source Description	Key Idea
Naresh and Thamarai (2023)	The sources discusses various privacy-preserving techniques for use in machine learning and AI	State-of-the-art applications can be used to ensure data mining, screening, publication, and distribution preserves and protects sensitive and private information
Zerka et al. (2020)	The source focuses on privacy-preserving distributed machine learning algorithms to address privacy concerns	Distributed machine learning from federated databases reduce the need for data centralization. The algorithms allow for traceability and transparency while ensuring adherence to FAIR data principles.
Khalid et al. (2023)	The study examines the privacy-preserving techniques and applications, as well as their limitations, in healthcare	Federated learning and hybrid techniques help address privacy problems
Siala and Wang (2022)	The research explores responsible AI initiatives that address privacy and ethical practice	Human-centric AI, which embeds humanness in AI helps address the requirements of ethics of care
Gerke et al. (2020)	The article explores ethical and legal challenges of AI-driven healthcare	The current developments in cybersecurity frameworks should help create ethical AI-driven products in healthcare.
Murphy et al. (2021)	The scoping review examines how AI can be used for good health	There is a possibility that AI can be made safe for use in healthcare.

The findings for this question can be considered inconclusive because they fail to offer an explicit answer to the question. A critical review of all the material available revealed that there is a possibility that machine learning and the broader AI tools for healthcare can be designed such they address the ethical and privacy issues. Only a few mechanisms have been proposed in literature. This leaves a massive gap that must be filled with primary empirical

research.

4.3. Governance and Policy Frameworks

This research found inadequate information regarding governance and policy frameworks unique to machine learning. However, all technologies in healthcare have been governed through policy and governance frameworks that seek to protect patient health information. In many cases, such frameworks have been considered the greatest barrier to the adoption of novel healthcare technologies. An important point to note is that the policy and governance frameworks are dynamic and change based on the technological development. In this research, the key policy and governance frameworks identified revolve around transparency, social sustainability, tradeoff between privacy and utility, documentation, and regulatory concerns. This research reiterates that the regulatory frameworks sets governance, ethical, and privacy standards that, while protecting patient health data, makes implementation of new technologies untenable.

Discussion

Research on the use of machine learning in care personalization is rapidly growing as new applications emerge. Patients with disabilities are among the most common users of assistive technologies, some of which have been designed using machine learning and other AI tools. This research explores how such applications affect issues of privacy and ethical practice. All technologies face these challenges due to the various vulnerabilities. As such, there is a real possibility that privacy breaches and unethical use could undo the benefits of machine learning. Multiple studies have explored this subject. As illustrated in the findings, over a hundred sources discussing privacy and ethics in care personalization were found. Most of these studies support what has been presented in the literature review. In essence, this research reveals that the successful deployment of machine learning and other AI tools in care personalization requires a careful balancing between the moral principles involving optimizing care and complex data-handling technologies[16]. Without such a balance, machine learning threatens to undermine care personalization detrimentally.

The research also supports the current literature regarding where the privacy and ethical challenges in machine learning emanate from. In this case, the fact that machine learning is used to handle data and is connected to devices used in collecting such data exposes the technology to ethical and privacy issues. Care personalization is a data-driven practice where predictive and analytics tools screen and process vast amounts of data from multiple sources to generate actionable insights. In many cases, the sources of such data are connected IoT devices, including wearable devices and surveillance tools. Without patient consent,

such practices are unethical and are considered an infringement of patient privacy. The findings screened from multiple sources indicated that accessing the data raises privacy issues. Other privacy-threatening practices involving machine learning include disseminating and sharing data.

Therefore, ethical and privacy issues associated with machine learning are not inherent to the technology itself, but its use raises the issues. This leaves a critical question not on how to resolve the issues but on whether and how machine learning can help address them. This is a question quickly attracting the attention of scholars and practitioners who believe that the predictive capabilities of machine learning can help learn about potential privacy breaches and help mitigate such risks. This research indicates that even though there is scant literature, there are hopes that machine learning could prove useful in this regard. Some studies used in this research revealed that artificial neural networks (ANNs), a subset of machine learning, are core to deep learning. ANNs can boost data privacy and security by adding new layers of protection to prevent breaches[32]. More empirical evidence is needed to make conclusive remarks regarding the extent to which machine learning can become a solution to ethical and privacy issues in care personalization.

The only area of this research without much supporting data was regarding the policy and governance frameworks for addressing privacy and ethical challenges of machine learning. This is explained by the considerably small number of sources found, and the fact that the research did not find evidence of specific policies and government frameworks to machine learning. Therefore, this research only indicated that the general policies and governance frameworks governing the use of technologies in healthcare are used in the context of machine learning. This is despite the fact that machine learning and other AI tools open up new paradigms in healthcare practice that go beyond mere automation and data management functions. Essentially, machine learning is the technology that makes AI technologies and tools smart because machine learning leverages advances in such areas as speech recognition, computer vision, and auditory scene analysis to interpret data and inform decision-making[6]. This means that from a policy and governance standpoint, machine learning should not be treated the same way as other healthcare technologies, including wearable devices, IoTs, or even electronic health records.

The need to emphasize policy and governance frameworks is that machine learning is increasingly becoming indispensable in healthcare due to the possibilities it offers and the healthcare problems it solves. Across many areas of application, machine learning proves to offer capabilities beyond other technologies, including those involved in data

management. For example, big data analytics tools can be integrated into electronic health records to help analyze patient health data for use in medical decision-making. However, such an arrangement would still require a significant level of human effort because such a technology is not smart. In many cases, legislation on privacy could be considered a hindrance to the deployment of machine learning in care personalization. This is because machine learning algorithms autonomously access data from various sources, process it, and generate actionable insights without much human input. Privacy policies and legislation restrict access and machine learning may not be effective without access to the data. This research reveals a massive gap in literature in this regard that must be addressed urgently.

Additionally, policy and governance in healthcare should adopt a patient-centered approach. Even though this research failed to obtain data on machine learning policies and governance frameworks, there were efforts to address how machine learning can contribute to policy-making in healthcare[33]. These studies acknowledge that machine learning can transform policy-making in healthcare similarly to how it facilitates aspects of healthcare – through data[31]. With adequate data and knowledge derived from screening massive volumes of data, health policy-makers can make proper healthcare predictions, improve risk management, and design effective health policies. Therefore, it can be argued that one of the areas where policy and governance frameworks are needed is regarding the use of machine learning itself in care personalization. The rationale is that machine learning is safer than most technologies currently used in healthcare and solves more health problems than any available technology. This is not to mean that lax measures and policies should be made. On the contrary, the policies and governance frameworks should be designed such that it becomes possible to exploit the full potential of machine learning in healthcare applications.

5. Conclusion and Recommendations

Machine learning is among the technologies that are becoming indispensable in care personalization for patients with disabilities. The capabilities of machine learning trump most practical technologies currently in use, especially the predictive and data mining capabilities. However, these advantages come at a major tradeoff: machine learning, like all other technologies, still raises ethical and privacy challenges. This study finds that the technology itself, the care practice, and data are all elements where the privacy and ethical issues arise. However, the primary conclusion drawn from the findings is that as long as a technology is used in healthcare to handle patient data, privacy and ethical problems will always arise. There is a possibility that machine learning, due to its predictive capabilities, can be used to address the ethical and privacy issues. However, the

findings of this study were not conclusive in this regard. Policy and governance frameworks for managing healthcare technologies still apply to machine learning and other AI-based health technologies.

The findings have also revealed major issues with the current state of literature regarding the subject. The main issue is that there are inadequate studies that examine all the elements of the research topic: machine learning, ethical and privacy issues, care personalization, and patients with disabilities. The scoping review was an attempt to reveal this problem and lay the foundation for future discourse. In this case, it is important to emphasize that the conclusions of this study are based on findings mostly inferred from studies that focus on the various elements separately. The literature review established that patients with disabilities are among the most common users of machine learning and other assistive technologies. Therefore, it can be expected that this area of research should attract adequate scholarly and practice attention. This study reveals that such attention is lacking, something that must change.

Machine learning is a promising technology for care personalization. However, the ethical and privacy issues may derail its deployment in healthcare, including care personalization for patients with disabilities. The main recommendation based on the research findings is that the healthcare industry should dedicate considerable resources and efforts in running clinical trials on care personalization using machine learning to test the extent to which the ethical and privacy issues apply. Such trials should also help test the extent to which machine learning can safely be utilized for care personalization without raising the ethical and privacy issues.

Another key recommendation is that there should be future research that examines the extent to which machine learning and other AI-based technologies can be used to address privacy and ethical issues. The rationale is that machine learning allows for predictive analytics – these analytics could be used to screen data, identify privacy and ethical risks, and either resolve them or flag them for human interventions. Such interventions are possible considering what machine learning entails. In this case, care personalization remains part of the future of health care, but the evidence-based approaches require use and handling of sensitive data.

References

- [1] Basu, T., Engel-Wolf, S., & Menzer, O. (2020). The ethics of machine learning in medical sciences: Where do we stand today? *Indian Journal of Dermatology*, 65(5), 358-364.
https://doi.org/10.4103%2Fijid.IJD_419_20
- [2] Carter, S. (2022). A Value-centered Exploration of Data Privacy and Personalized Privacy Assistants. *DISO*, 1(27). <https://doi.org/10.1007/s44206-022-00028-w>
- [3] Cirillo, D., & Valencia, A. (2019). Big data analytics for personalized medicine. *Current Opinion in Biotechnology*, 58, 161-167. <https://doi.org/10.1016/j.copbio.2019.03.004>
- [4] Cordeiro, J. (2014). Ethical and legal challenges of personalized medicine: Paradigmatic examples of research, prevention, diagnosis and treatment. *Revista Portuguesa de Saúde Pública*, 32(2), 164-180. <https://doi.org/10.1016/j.rpsp.2014.10.002>
- [5] Deruelle, T., Kalouguina, V., Trein, P., & Wagner, J. (2023). Designing privacy in personalized health: An empirical analysis. *Big Data and Society*, 1-9. <https://doi.org/10.1177/20539517231158636>
- [6] Domingo, M. (2021). An overview of mMachine learning and 5G for people with disabilities. *Sensors*, 21(22). <https://doi.org/10.3390%2Fs21227572>
- [7] Fang, K., & Ping, C. (2022). Using machine learning to explore the crucial factors of assistive technology assessments: Cases of wheelchairs. *Healthcare (Basel)*, 10(11). <https://doi.org/10.3390%2Fhealthcare10112238>
- [8] Farhud, D., & Zokaei, S. (2021). Ethical issues of artificial intelligence in medicine and healthcare. *Iranian Journal of Public Health*, 50(11). <https://doi.org/10.18502%2Fijph.v50i11.7600>
- [9] Gerke, S., Minssen, T., & Cohen, G. (2020). Ethical and legal challenges of artificial intelligence-driven healthcare. *Artificial Intelligence in Healthcare*, 295-336. <https://doi.org/10.1016%2FB978-0-12-818438-7.00012-5>
- [10] Guo, A., Kamar, E., Vughan, J., Wallach, H., & Morris, M. (2019). Toward fairness in AI for people with disabilities: A research roadmap. *ACM SIGACCESS Accessibility and Computing*. <https://doi.org/10.1145/3386296.3386298>
- [11] Heyen, N., & Salloch, S. (2021). The ethics of machine learning-based clinical decision support: an analysis through the lens of professionalisation theory. *BMC Medical Ethics*, 22(112). <https://doi.org/10.1186/s12910-021-00679-3>
- [12] Khalid, N., Qayyum, A., Bilal, M., Al-Fuqaha, A., & Qadir, J. (2023). Privacy-preserving artificial intelligence in healthcare: Techniques and applications. *Computers in Biology and Medicine*, 158.

<https://doi.org/10.1016/j.compbimed.2023.106848>

- [13] Khan, O., Badhiwala, J., Grasso, G., & M., F. (2020). Use of machine learning and artificial intelligence to drive personalized medicine approaches for spine care. *World Neurosurgery*, 140, 512-518. <https://doi.org/10.1016/j.wneu.2020.04.022>
- [14] Klein, E., Kinsella, M., Stevens, I., & Fried-Oken, M. (2022). Ethical issues raised by incorporating personalized language models into brain-computer interface communication technologies: a qualitative study of individuals with neurological disease. *Disability and Rehabilitation: Assistive Technology*, 1-11. <https://doi.org/10.1080/17483107.2022.2146217>
- [15] Lillywhite, A., & Wolbring, G. (2021). Coverage of ethics within the artificial intelligence and machine learning academic literature: The case of disabled people. *Assistive Technology*, 33(3), 129-135. <https://doi.org/10.1080/10400435.2019.1593259>
- [16] Maeckelberghe, E., Zdunek, K., Marceglia, S., & Frsides, B. (2023). The ethical challenges of personalized digital health. *Frontiers in Medicine*, 10, 1-14. <https://doi.org/10.3389/fmed.2023.1123863>
- [17] Mehta, N., Pandit, A., & Shukla, S. (2019). Transforming healthcare with big data analytics and artificial intelligence: A systematic mapping study. *Journal of Biomedical Informatics*, 100. <https://doi.org/10.1016/j.jbi.2019.103311>
- [18] Mulfari, D., Meoni, G., Marini, M., & Fanucci, L. (2021). Machine learning assistive application for users with speech disorders. *Applied Soft Computing*, 103. <https://doi.org/10.1016/j.asoc.2021.107147>
- [19] Murphy, K., Ruggiero, E., Upshur, R., Willison, D., Malhotra, N., Cai, J., . . . Gibson, J. (2021). Artificial intelligence for good health: A scoping review of the ethics literature. *BMC Medical Ethics*, 22(14). <https://doi.org/10.1186/s12910-021-00577-8>
- [20] Namoun, A., Sen, A., Tufail, A., Alshantiti, A., Nawaz, W., & BenRhouma, O. (2022). A two-phase machine learning framework for context-aware service selection to empower people with disabilities. *Sensors*, 22(14), 1-29. <https://doi.org/10.3390/s22145142>
- [21] Naresh, V., & Thamarai, M. (2023). Can machine learning help address ethical and privacy issues in care personalization efforts targeting people with disabilities? *WIREs Data Mining and Knowledge Discovery*, 13(2). <https://doi.org/10.1002/widm.1490>
- [22] Peters, M., Godfrey, C., Mcinerney, P., Soares, C., Khalil, H., & Parker, D. (2015). Methodology for JBI scoping reviews. In *The Joanna Briggs Institute reviewers' manual 2015* (pp. 1-24). Joanna Briggs Institute.
- [23] Schleidgen, S., & Marckmann, G. (2013). Re-focusing the ethical discourse on personalized medicine: a qualitative interview study with stakeholders in the German healthcare system. *BMC Medical Ethics*, 20. <https://doi.org/10.1186/1472-6939-14-20>
- [24] Seifert, A., & Vandelanotte, C. (2021). The use of wearables and health apps and the willingness to share self-collected data among older adults. *Aging and Health Research*, 1(3). <https://doi.org/10.1016/j.ahr.2021.100032>
- [25] Siala, H., & Wang, Y. (2022). SHIFTing artificial intelligence to be responsible in healthcare: A systematic review. *Social Science & Medicine*, 296. <https://doi.org/10.1016/j.socscimed.2022.114782>
- [26] Tenny, S., Brannan, J., & Brannan, G. (2022). Qualitative study. *StatPearls*.
- [27] Wald, M. (2021). AI data-driven personalisation and disability inclusion. *Frontiers in Artificial Intelligence*, 6, 1-7. <https://doi.org/10.3389/frai.2020.571955>
- [28] Wangmo, T., Lipps, M., Kressig, R., & Lenca, M. (2019). Ethical concerns with the use of intelligent assistive technology: findings from a qualitative study with professional stakeholders. *BMC Medical Ethics*, 20(98). <https://doi.org/10.1186/s12910-019-0437-z>
- [29] Wu, Y., Zhang, L., Bhatti, U., & Huang, M. (2023). Interpretable machine learning for personalized medical recommendations: A LIME-based approach. *Diagnostics*, 13(16), 1-23. <https://doi.org/10.3390/diagnostics13162681>
- [30] Yang, F., & Guo, X. (2022). Research on rehabilitation effect prediction for patients with SCI based on machine learning. *World Neurosurgery*, 158, e662-e674. <https://doi.org/10.1016/j.wneu.2021.11.040>
- [31] Ashrafian, H., & Darzi, A. (2018). Transforming health policy through machine learning. *PLoS Medicine*, 5(11). <https://doi.org/10.1371/journal.pmed.1002692>
- [32] Jogannathan, J., & Parvees, M. (2022). Security breach prediction using Artificial Neural Networks. *Measurement: Sensors*, 24. <https://doi.org/10.1016/j.measen.2022.100448>
- [33] Varon, L., Gonzalez-Puelma, J., Medina-Ortiz, D., Aldridge, J., Alvarez-Saravia, Uribe-Paredes, R., & Navrete, M. (2023). The role of machine learning in health policies during the COVID-19 pandemic and in long COVID management. *Frontiers in Public Health*, 11. <https://doi.org/10.3389/fpubh.2023.1140353>