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Challenges to patients' rights during the COVID-19 pandemic: survey of public perceptions in North Macedonia

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Abstract

The COVID-19 pandemic exposed significant challenges in upholding patient rights within Macedonian healthcare system. An online survey of 145 citizens assessed their perceptions regarding access to healthcare, informed consent, autonomy, and privacy during the pandemic. Results showed that 65.5% of respondents had access to essential services and 95.2% did not experience discrimination. Although 72.4% felt adequately informed about their care throughout all phases, just under half (47.6%) were aware of their healthcare and insurance rights and the procedures to secure them. Two-thirds (67.6%) reported that their autonomy was respected despite restrictive measures, and over 70% believed their privacy was maintained. These findings highlight both strengths and areas for improvement, emphasizing the need for enhanced and detailed delivery of information by healthcare professionals. Addressing these issues is crucial for refining healthcare policies and practices, ensuring equitable and effective care, and better protecting patient rights during future public health emergencies in North Macedonia.

Key words: patients' rights, COVID-19, aceess to healthcare, informed consent, privacy, autonomy

Introduction

The COVID-19 pandemic has fundamentally altered the landscape of global healthcare, highlighting the importance of patient rights in public health emergencies (Sekalala et al, 2020). As the virus rapidly spread worldwide, healthcare systems faced immense pressure, revealing weaknesses in both developed and developing countries (Chippaux, 2023; DeSalvo et al., 2021; Filip et al., 2022). The overwhelming demand for medical services created significant challenges in healthcare delivery, forcing healthcare providers and governments to make quick and hard decisions. While necessary to protect public health, these decisions often involved balancing urgent public health needs with the fundamental rights of patients. As a result, the pandemic has examined the robustness of current legal, ethical, and human rights frameworks, generating essential discussions about the best methods to protect patients' rights during public health emergencies (Pūras et al., 2020).

The COVID-19 pandemic has brought to light severe challenges regarding the right to access healthcare, a basic principle that was put to the test in ways rarely seen before. As hospitals and clinics became overloaded with COVID-19 cases, many healthcare systems were obliged to focus

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on managing the pandemic, often at the expense of other medical services. This shift in focus led to the postponement of elective surgeries, delays in routine medical examinations, and a reduction in the availability of non-urgent healthcare services (Adachi et al., 2023; Czeisler et al., 2020; Schwarz et al., 2020). As a result, patients with chronic conditions or those in need of ongoing medical care frequently experienced disruptions in their treatment. This interruption in hospital care, accompanied with drug shortages, led to worsening of existing health problems in some patients, illustrating the broad impact of the pandemic on patient health beyond the direct effects of the virus (Tarawneh et al., 2024; Ullah et al., 2021). The pandemic has also exposed profound disparities in healthcare access, particularly affecting marginalized and vulnerable groups. People from low-income communities, racial and ethnic minorities, seniors, and individuals with disabilities often encountered significant challenges in obtaining the needed medical care (Maizel et al., 2024; Polinesi et al., 2023). These groups were disproportionately affected, with higher COVID-19 morbidity and mortality, which highlighted established inequalities in the allocation of healthcare resources. The situation was even worse in areas where healthcare systems were already underfunded, emphasizing the urgent need for policies that provide fair access to healthcare for everyone, regardless of their economic status or affiliation with a particular community (Andraska et al., 2021).

Another important aspect of patient rights that was heavily analyzed during the COVID-19 pandemic is the right to informed consent (Rothwell et al., 2021). The rapid development and rollout of new treatments and vaccines, posed significant ethical questions regarding informed consent. Because knowledge about the virus and its treatments was changing rapidly, patients often had to make quick decisions about their care, sometimes without fully understanding the associated risks and benefits. This issue was particularly challenging in cases where vaccines and treatments were authorized for emergency use, as the usual comprehensive procedures for patient education and obtaining informed consent were often shortened. Despite the urgency of a public health crisis, it remains essential to provide patients with clear, accurate, and timely information to maintain ethical standards around informed consent (Mcquoid-Mason, 2020; Milo, 2023).

Additionally, the principle of patient autonomy became a contentious issue throughout the pandemic. Public health measures, including lockdowns, mandatory COVID-19 testing in order to leave the country, quarantine requirements, and vaccination directives, were essential for controlling the virus's spread but were also viewed by some as violations on individual freedoms (Gostin and Wiley, 2020). This tightness led to considerable debate about the limits of personal autonomy in the context of a public health crisis and the extent to which the authorities can enforce restrictions to protect the health of the broader community (Valutytė et al., 2021). Balancing individual rights with collective responsibilities continues to present a complex ethical challenge, particularly in times of widespread crisis (Gómez-Vírseda and Usanos, 2021).

Privacy and confidentiality, which are central aspects of patient rights, faced significant challenges during the pandemic. The widespread adoption of digital health technologies, such as contact tracing apps and online health platforms, was crucial in managing the spread of the virus. However, these technologies also raised serious concerns about data privacy and the potential misuse of personal health information (Bérar and Bouvet, 2023). There were instances where patient data was shared without proper consent or where data protection measures fell short, highlighting an urgent need for stringent safeguards to ensure patient privacy, especially during public health emergencies (Newlands et al., 2020).

During the COVID-19 pandemic, North Macedonia's commitment to protect patient rights, as outlined in the 2008 Law on the Protection of Patients' Rights (Law on the Protection of Patients' Rights, Official Gazette of the Republic of Macedonia, №. 82/2008, 12/2009, 53/11, 150/15 and 190/19), was seriously challenged. This law, along with the country's ratification of various international human rights treaties (Alcheva et al., 2013), played a crucial role in guiding the healthcare response, emphasizing the importance of patient access to care, the right to privacy, and the need for transparent communication between healthcare providers and patients. Therefore, the aim of this research was to evaluate the perception of the citizens of the Republic of North Macedonia regarding patients' rights for the period of the COVID-19 pandemic, underlining the weaknesses of the country's healthcare system in this context and establishing a foundation for further improvement.

Material and methods

An online questionnaire comprising 18 questions, divided into two sections, was developed to assess the perceptions of citizens in the Republic of North Macedonia about patients' rights during the COVID-19 pandemic. The first section addressed the general demographic characteristics of the participants, while the second focused on their views regarding fundamental patients' rights throughout the pandemic. The survey included 145 participants, of which 52 (35.9%) men and 93 (64.1%) women, each allowed to complete the questionnaire only once. Of the respondents, 44 (30.3%) were over 40 years old, and 101 (69.6%) were between the ages of 18 and 40. The vast majority of participants identified as Macedonians (n=128; 86.2%), were residents of urban areas (n=124; 85.5%), and all had completed at least high school education. Almost one-third of the volunteers who completed the questionnaire were healthcare workers, and over two-thirds reported having received at least one dose of a COVID-19 vaccine. The second section of the

questionnaire focused on participants' views regarding key patient rights, including access to medical care, informed consent, autonomy, and confidentiality. This analysis helps reveal the difficulties healthcare system in North Macedonia encountered in maintaining patient rights during the crisis.

Results and discussion

The results of this study offer a valuable insight into the perspectives of the citizens of the Republic of North Macedonia about patients' rights in the context of COVID-19. This study provides an understanding of several essential concerns that arose before, during, and after the crisis regarding healthcare access, consent, patient-centered decisions, and confidentiality. To successfully implement policies related to patients' rights, careful consideration of general population opinion is required, and the COVID-19 pandemic has enabled just such detection of implementation and practice inconsistencies and potential discrepancies with existing regulations. The survey results are summarized in Table 1.

Macedonia's healthcare system remains highly centralized, even though the country has been working on decentralization across various sectors since 2001. This centralization limits access to healthcare, especially for marginalized groups, as there are significant geographic differences in the availability of services (Gjorgjev et al., 2006, Tairi and Tozija, 2019). Despite the Law on the Protection of Patients' Rights guaranteeing access to quality healthcare in the country, many vulnerable groups face significant barriers. For instance, despite the Macedonian government's provision of compulsory state-funded healthcare, Roma patients, including pregnant women, often face discrimination, substandard care, physical violence, and are sometimes required to pay for services that should be free, with racial prejudice playing a significant role in their mistreatment (Salioska et al., 2017). Furthermore, over 60% of rural women lack easy access to gynecological services, highlighting disparities in healthcare availability (Alcheva et al., 2013). Despite the well-documented challenges facing the healthcare system in the country, nearly two-thirds (65.5%) of respondents in our survey reported having access to essential healthcare services during the pandemic. Furthermore, the vast majority (95.2%) stated that they did not experience any discrimination when seeking healthcare services during this time, and over 80% reported that they neither experienced nor witnessed inhumane or degrading treatment by healthcare providers during the pandemic. However, these findings may be influenced by the demographics of the respondents, the majority of whom resided in urban areas with well-developed healthcare infrastructure, were generally young and well-educated and belonged to the country's majority ethnic group.

Under the Law on the Protection of Patients' rights, patients are entitled to comprehensive and understandable information about their health condition, recommended medical interventions, associated risks and benefits, alternatives, potential outcomes, procedural details, lifestyle recommendations, their healthcare and insurance rights, the credentials of the healthcare professionals providing their care. In a study, performed briefly before the pandemic in hospitals in the Polog region, it was observed that 85.2% of the surveyed patients were informed about the recommended medical interventions (Tairi and Tozija, 2019). In our survey, slightly fewer respondents (72.4%) indicated that they were informed about aforementioned aspects throughout all phases of health care, while only half (51.0%) were aware of the names, professional training, and specialization of the health workers who provided their immediate care. Close to half of the participants (47.6%) reported being familiar with their rights to health care and health insurance, as well as the procedure for securing those rights. Closely related to the right to information, our study also asked respondents about their right to inspect their medical file. Here, 73.1% indicated that they were given the opportunity to do so, while a notable 98.6% reported that no research or involvement in medical teaching occurred without their prior consent. Rights related to personal autonomy were significantly impacted during the COVID-19 pandemic. According to the Law on Patients' Rights, the right to make decisions, in conjunction with the right to be informed, forms the basis of a patient's right to participate in healthcare decisions. Patients are entitled to accept or refuse medical interventions, except in cases where delaying or forgoing the intervention would pose a risk to their life or health, or the life and health of others, or could result in temporary or permanent harm. To safeguard public health, North Macedonia, like other European countries, imposed measures such as mandatory isolation for COVID-19-positive individuals, testing requirements for hospital admissions or travel, and vaccination mandates for access to public venues. Despite these restrictions, two-thirds of respondents (67.6%) in our study reported that they did not feel deprived of their right to make medical decisions. However, this outcome may be influenced by the demographics of our respondents, who were predominantly vaccinated, young, and educated. This could be associated with a better understanding and acceptance of the public health measures enforced by the authorities.

During the COVID-19 pandemic, issues surrounding confidentiality and privacy rights were frequently debated. Early in the pandemic, journalistic reports often indirectly revealed the identities of COVID-19 patients, and social media further exacerbated this by frequently disclosing patient identities. Although contact-tracing apps were not widely used in North Macedonia, they still posed challenges to patients' privacy rights. Despite these concerns, our survey found that over 70% of respondents believed their right to confidentiality of personal and

Table 1. A survey of patient perception of patients' rights in in Republic of North Macedonia during COVID-19 pandemic

Questions	Answers (%)	
	Yes	No
Did you experience uninterrupted and continuous access to essential health care services during the COVID-19 pandemic?	65.5	34.5
Did you experience or encounter any form of discrimination by healthcare professionals at the healthcare facility where you were receiving care during the COVID-19 pandemic?"	95.2	4.8
Have you witnessed any form of inhumane or degrading behavior by medical staff towards you or other patients during the COVID-19 pandemic?	82.8	17.2
Was the right to be informed upheld throughout all stages of healthcare during the COVID-19 pandemic?	72.4	27.6
Were you informed about the names, qualifications, and specializations of the healthcare professionals who provided you with direct healthcare during the COVID-19 pandemic?	51.0	49.0
During the COVID-19 pandemic, were you informed about your rights concerning healthcare and health insurance, as well as the procedures for exercising those rights?	47.6	52.4
During the COVID-19 pandemic, was your right to access your medical records respected?	73.1	26.9
During the COVID-19 pandemic, were you involved in scientific research or medical education activities without having provided explicit consent?	98.6	1.4
Was the right to accept or decline specific medical interventions respected during the COVID-19 pandemic?	67.6	32.4
Was the right to confidentiality of personal and medical information respected during the COVID-19 pandemic?	73.8	26.2
Was the right to conditions ensuring privacy during medical interventions, particularly when receiving personal care, respected during the COVID-19 pandemic	75.2	24.8

medical data was upheld, with 73.8% affirming respect for this right and 75.2% confirming that privacy was maintained during medical interventions, particularly in the context of personal care.

The major strength of this study is that it is one of the few initiatives in North Macedonia aimed at evaluating citizens' perspectives on patients' rights during the COVID-19 pandemic. By gathering data directly from citizens, the study provides valuable insights into the organization and functioning of the healthcare system during this critical period, particularly with regard to key patients' rights such as access to care, information, decision-making, and patient confidentiality.

However, there are several limitations that should be

pointed out. The survey was conducted online and this may have left out older adults and inhabitants of rural areas who may have had a different experience regarding their rights as patients. Furthermore, majority of the respondents were young, living in urban areas, with relatively high education levels, which can be considered as a source of bias because such people have improved access to healthcare services. In addition, the high number of respondents who were healthcare workers might have skewed the results in some way since their experiences may not be typical of the general populace. Finally, because of the small number of participants, the results cannot be generalized to the total population of North Macedonia.

References

Adachi, K., Kimura, F., Takahashi, H., Kaise, H., Yamada, K., Ueno, E., Kawate, T., Miyahara, K., Ueda, A., Sato, S., Asaoka, M., Okazaki, M., Uenaka, N., Orimoto, K., Wu, R., Koyama, Y., Ishikawa, T., 2023. Delayed Diagnosis and Prognostic Impact of Breast Cancer During the COVID-19 Pandemic. Clin. Breast Cancer 23(3), 265-271. doi: 10.1016/j.clbc.2023.01.001.

Alcheva, G., Gerovski, F., Beletsky, L., 2013. Implementation of Patients' Rights Legislation in the Republic of Macedonia: Gaps and Disparities. Health Hum Rights 15(2), 20-31. https://ssrn.com/abstract=2367295

Andraska, E.A., Alabi, O., Dorsey, C., Erben, Y., Velazquez, G., Franco-Mesa, C., Sachdev, U., 2021. Health care disparities during the COVID-19 pandemic. Semin. Vasc. Surg. 34(3), 82-88. doi:10.1053/j.semvascsurg.2021.08.002

Bérar, A., Bouvet, R., 2023. Confidentiality of health data in contact tracing systems during the Covid-19 pandemic in France. Int. Data Priv. Law 13(2), 141–153. https://doi.org/10.1093/idpl/ipad004

Chippaux, J.P., 2023. COVID-19 impacts on healthcare access in sub-Saharan Africa: an overview. J. Venom Anim. Toxins Incl. Trop. Dis. 29, e20230002. doi:10.1590/1678-9199-JVATITD-2023-0002.

Czeisler, M.É., Marynak, K., Clarke, K.E.N., Salah, Z., Shakya, I., Thierry, J.M., Ali, N., McMillan, H., Wiley, J.F., Weaver, M.D., Czeisler, C.A., Rajaratnam S.M.W., Howard, M.E., 2020. Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns - United States, June 2020. Morb. Mortal Wkly Rep. 69(36), 1250-1257. doi:10.15585/mmwr.mm6936a4.

DeSalvo, K., Hughes, B., Bassett, M., Benjamin, G., Fraser, M., Galea, S., Gracia, J.N., 2021. Public Health COVID-19 Impact Assessment: Lessons Learned and Compelling Needs. NAM Perspect. 10.31478/202104c. doi:10.31478/202104c.

Filip, R., Gheorghita, P. R., Anchidin-Norocel, L., Dimian, M., Savage, W.K., 2022. Global Challenges to Public Health Care Systems during the COVID-19 Pandemic: A Review of Pandemic Measures and Problems. J. Pers. Med. 12(8), 1295. doi:10.3390/jpm12081295.

Gjorgjev, D., Bacanovic, A., Cicevalieva, S., 2006. The former Yugoslav Republic of Macedonia: Health system review. Health syst. transit 8(2), 27. http://www.euro.who.int/__data/assets/pdf_file/0005/96413/E89275.

Gómez-Vírseda, C., Usanos, R.A., 2021. Relational autonomy: lessons from COVID-19 and twentieth-century philosophy. Med. Health Care and Philos. 24, 493–505. https://doi.org/10.1007/s11019-021-10035-2

Gostin, L.O., Wiley, L.F., 2020. Governmental Public Health Powers During the COVID-19 Pandemic Stay-at-home Orders, Business Closures, and Travel Restrictions. JAMA 323(21), 2137-2138. doi:10.1001/jama.2020.5460

Maizel, J.L., Haller, M.J., Maahs, D.M., Addala, A., Lal, R.A., Filipp, S.L., Gurka, M.J., Westen, S., Dixon, B.N., Figg L., Hechavarria, M., Malden, K.G., Walker, A.F., 2024. COVID-19 impacts and inequities among underserved communities with diabetes. J. Clin. Transl. Endocrinol. 36, 100337. doi: 10.1016/j.jcte.2024.100337.

Mcquoid-Mason, D.J., 2020. COVID-19 and its impact on informed consent: What should health professionals tell their patients or their proxies? S. Afr. j. bioeth. Law 13(1), 7-10. ID: biblio-1270212

Milo, C., 2023. COVID-19 Vaccination and the Role of Informed Consent: England as a Case Study. Eur. J. Public Health 30(4), 428-448. https://doi.org/10.1163/15718093-bja10108

Newlands, G., Lutz, C., Tamò-Larrieux, A., Villaronga, E. F., Harasgama, R., Scheitlin, G., 2020. Innovation under pressure: Implications for data privacy during the Covid-19 pandemic. BD&S 7(2). https://doi.org/10.1177/2053951720976680

Official Gazzette of the Republic of Macedonia № 82/2008, 12/2009, 53/11, 150/15 and 190/19, Law on the Protection of Patients' Rights, Available at: https://zdravstvo.gov.mk/zakon-za-zashtita-na-prava-na-pacienti/ (assessed on September 9th 2024).

Polinesi, G., Ciommi, M., Gigliarano, C., 2023. Impact of COVID-19 on elderly population well-being: evidence from European countries. Qual Quant. https://doi.org/10.1007/s11135-023-01656-1

Pūras, D., de Mesquita, J.B., Cabal, L., Maleche, A., Meier, B.M., 2020. The right to health must guide responses to COVID-19. The Lancet 395(10241), 1888-1890. doi:10.1016/S0140-6736(20)31255-1

Rothwell, E., Brassil, D., Barton-Baxter, M., Brownley, K.A., Dickert, N.W., Ford, D.E., Kraft, S.A., McCormick, J.B., Wilfond, B.S., 2021. Informed consent: Old and new challenges in the context of the COVID-19 pandemic. J. Clin. Transl. Sci. 5(1), e105. doi: 10.1017/cts.2021.401.

Salioska, N., Lee, T.T., Quinn, R., 2017. Advancing human rights in patient care of Roma: access to health insurance in Macedonia. Public Health Rev. 38, 16. https://doi.org/10.1186/s40985-017-0064-5

Schwarz, V., Mahfoud, F., Lauder, L., Reith, W., Behnke,, S., Smola S., Rissland, J., Pfuhl, T., Scheller, B., Böhm,, M., Ewen, S., 2020. Decline of emergency admissions for cardiovascular and cerebrovascular events after the outbreak of COVID-19. Clin. Res. Cardiol. 109(12), 1500-1506. doi: 10.1007/s00392-020-01688-9.

Sekalala, S., Forman, L., Habibi, R., Meier, B.M., 2020. Health and human rights are inextricably linked in the COVID-19 response. BMJ Global Health 5, e003359. doi:10.1136/bmjgh-2020-003359

Tairi, M., Tozija, M., 2019. Improvement of human rights in patient care in Republic of Macedonia. Arch. Pub. Health 11(1), 6-19. https://www.id-press.eu/aph/article/view/2842/3149

Tarawneh, O.H., Garay-Morales, S., Liu,, I.Z., Pakhchanian H.,

Kazim,, S.F., Roster K., McDaniel, L., Tabaie, S.A., Vellek, J., Raiker, R., Schmidt, M.H., Bowers, C.A., Tannoury, T., Tannoury, C., 2024. Impact of COVID-19 on Spinal Diagnosis and Procedural Volume in the United States. Global Spine J. 14(6), 1714-1727. doi:10.1177/21925682231153083

Ullah, I., Hassan, W., Tahir, M.J., Ahmed, A., 2021. Antiretrovirals shortage in Kenya amid COVID-19. J. Med. Virol. 93(10), 5689-5690. doi: 10.1002/jmv.27134.

Valutytė, R., Jočienė, D., Ažubalytė, R., 2021. Legality of Human Rights Restrictions During the COVID-19 Pandemic Under the European Convention on Human Rights. TiLR. 26(1), 1–15. https://doi.org/10.5334/tilr.245.

Резиме

Предизвици за правата на пациентите за време на пандемијата со COVID-19: истражување на јавните перцепции во Република Северна Македонија

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Клучни зборови: права на пациенти, COVID-19, пристап до здравствена заштита, инфофмирана согласност, приватност, автономија

Пандемијата предизвикана од COVID-19 наметна значајни предизвици врз заштитата на правата на пациентите во рамките на здравствениот систем на Република Северна Македонија. Студијата, во која учествуваа 145 испитаници, ги процени нивните согледувања за почитувањето на основните принципи на непречен пристап до здравствена заштита, правото на информирана согласност, личната автономија и правото на приватност и доверливост. Резултатите од студијата покажуваат дека 65,5% од испитаниците имале пристап до основните здравствени услуги, додека 95,2% од нив не се соочиле со дискриминација во здравствените установи за време на пандемијата. Иако 72,4% од учесниците сметаат дека биле соодветно информирани во однос на планираната медицинска грижа, помалку од половината (47,6%) биле запознаени со нивните права за здравствената заштита и осигурување, како и со постапките за нивно обезбедување. Две третини (67,6%) од испитаниците забележале дека нивната лична автономија била генерално почитувана и покрај рестриктивните мерки воведени од властите, додека над 70% веруваат дека нивната приватност била соодветно гарантирана во периодот на пандемијата. Овие наоди ги истакнуваат силните страни, но ги потенцираат и областите од законот за правата на пациентите кои бараат подобрување, јасно нагласувајќи ја потребата за поотворено и подетално обезбедување информации од страна на здравствените работници. Решавањето на овие прашања е од клучно значење за унапредување на политиките и практиките области на здравствената заштита, со цел да се обезбеди правична и ефикасна грижа, како и подобра заштита на правата на пациентите во идните вонредни здравствени ситуации.