

# Introduction

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## Introduction

The right to health is a fundamental component of our human rights and a dignified life. The right to enjoy the highest attainable standard of physical and mental health was first articulated at the international level in the 1946 Constitution of the World Health Organization, whose preamble defines health as »a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity«. Further, the preamble states that: »The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition«.<sup>1</sup>

The 1948 Universal Declaration of Human Rights also mentions health as part of the right to an adequate standard of living (Art. 25, para. 1): »Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in the circumstances beyond his control«.<sup>2</sup>

The right to the enjoyment of the highest attainable standard of physical and mental health was again recognized in 1966 in the International Covenant on Economic, Social and Cultural Rights.<sup>3</sup> »Since then, other international human rights treaties have recognized or referred to the right to health or elements of it, such as the right to medical care. The right to health is relevant to all States; every State has ratified at least one international human rights treaty that recognizes the right to health. Moreover, States have committed to protect-

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<sup>1</sup> Constitution of the World Health Organization. New York, 22.7.1946 (Off. Rec. Wld Hlth Org., 2, 100).

<sup>2</sup> Universal Declaration of Human Rights. Paris, United Nations General Assembly, 10.12.1948.

<sup>3</sup> International Covenant on Economic, Social and Cultural Rights, Article 12. Geneva, Switzerland: United Nations Human Rights Office.

ing this right through international declarations, domestic legislation and policies, and at international conferences.«<sup>4</sup>

Medical professionals provide services to a wide range of populations. Through these services, they contribute to the provision of the benefits secured by the right to health. In providing health services, they must deal with many types of diversity, biological as well as cultural, racial, ethnic, national, linguistic, gender and sexual orientation, religious, or socioeconomic. The needs of diverse populations require personalized approaches and, in many cases, additional measures to protect vulnerable individuals and groups. Since the right to health is a human right, it is clear that diversity encountered by health workers should never be a cause of inequity. To a significant degree, inequalities in health stem from the social determinants of health. Social determinants of health are the conditions in which people live, grow up, work and age. These include economic stability, physical environment, education, food sources, community and social environment, and availability of healthcare for patients. The World Health Organization defines several social determinants of health, such as income and social protection, education, unemployment and job security, working life conditions, food insecurity, housing, basic amenities and environment, early childhood development, social support and inclusion, structural conflict, and access to affordable health services of adequate quality.<sup>5</sup>

Diversity in healthcare refers to various personal characteristics, such as race, ethnicity, gender, sexual orientation, sexual identity, age, religion, political beliefs, education, physical abilities and disabilities, pregnancy, parenthood, socioeconomic background, property status, language, culture, and other personal circumstances.

Addressing diversity in healthcare requires cultural competence, i.e. the ability of healthcare providers to offer services that meet the unique social, cultural, and linguistic needs of their patients. Patients that are well understood and properly represented can receive better treatment.<sup>6</sup> »Cultural competence is the ability to act ethically and effectively in personal and professional cross-cultural settings. It re-

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<sup>4</sup> The Right to Health. Fact Sheet No. 31. Office of the United Nations High Commissioner for Human Rights, World Health Organization, 2008.

<sup>5</sup> World Health Organization: Social determinants of health. [https://www.who.int/health-topics/social-determinants-of-health#tab=tab\\_1](https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1) (accessed 17. 12. 2020).

<sup>6</sup> Alyssa Jordan: The Importance of Diversity in Healthcare & How to Promote It. Understanding the Benefits of Diversity for the Healthcare Workforce and for Pa-

quires awareness of one's cultural values and worldview and their implications to make respectful, reflective, and reasoned decisions, including the ability to imagine and collaborate across cultural boundaries.«<sup>7</sup> Cultural and linguistic competence is a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals. Cultural competence ensures effective, equitable, understandable, and respectful quality of care and services that are responsive to diverse health-related beliefs and practices, preferred languages, health literacy, and other communication needs.<sup>8</sup> Cultural competence can be descriptively put in terms that comprise of concepts such as cultural sensitivity, cultural responsiveness, cultural awareness, cultural effectiveness, cultural humility, and cultural literacy.<sup>9</sup> Several factors are required to provide culturally and linguistically appropriate standards of care; these encompass among others understandable and respectful care, diverse staff and leadership, ongoing language education and training, assistance services and right to language assistance services.<sup>10</sup> However, the catalogue of these aspects is much longer – further factors such as organiza-

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tients. Provo College, June 17, 2020, <https://www.provocollege.edu/blog/the-importance-of-diversity-in-healthcare-how-to-promote-it/> (accessed 17.12.2020).

<sup>7</sup> Juanita Sherwood: What is cultural competence? Sydney, The University of Sydney, National Centre for Cultural Competence, <https://www.sydney.edu.au/nccc/about-us/what-is-cultural-competence.html> (accessed 17.12.2020); Somayeh Alizadeh, Meena Chavan: Cultural competence dimensions and outcomes: a systematic review of the literature. In: *Health and Social Care in the Community* 24 (2015), pp. e117–e130, <https://doi.org/10.1111/hsc.12293>.

<sup>8</sup> The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care, Office of Minority Health, US Department of Health and Human Services, April 2013; The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care, A Blueprint for Advancing and Sustaining CLAS Policy and Practice Office of Minority Health, US Department of Health and Human Services, April 2013, p. 13; Terry L. Cross, Barbara J. Bazron, Karl W. Dennis, Mareasa R. Isaacs: *Towards a Culturally Competent System of Care. A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*. Washington, DC, Georgetown University Child Development Center 1989.

<sup>9</sup> *Cultural Competency and Tuberculosis Care. A guide for self-study and self-assessment*. Newark, New Jersey, The New Jersey Medical School Global Tuberculosis Institute 2008, p. 6. <http://globaltb.njms.rutgers.edu/downloads/products/Newsletter-7.pdf> (accessed 17.12.2020).

<sup>10</sup> Cultural Competency (Note 9), p. 60; Fabricio E. Balcazar, Yolanda Suarez-Balcazar, Tina Taylor-Ritzler: Cultural competence: Development of a conceptual framework. In: *Disability and Rehabilitation*, 31 (2009), pp. 1153–1160.



tional self-assessments, patient/client data, community profile, community partnerships, implementation of conflict/complaint processes complement this list and still leave open place for new factors.<sup>11</sup> The HERA »Public Spaces, Culture and Integration in Europe Programme« had recognized the increased social importance of the issues of right to health and diversity in healthcare. The group of researchers cooperating in the HERA research project »Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe« produced a volume on diversity and access to healthcare. It focuses on diversity and access to healthcare for minority groups in the context of hospital and clinical healthcare. The book focuses in particular on the concept of diversity, which includes ethnicity, religion, gender, sexual orientation, poverty, and age in the specific context of healthcare in Slovenia, Croatia, and Germany.

This volume of thirteen scholarly contributions is divided into three sections: minorities, migration, and poverty and vulnerable individuals and groups. In their contributions, twenty-seven authors have interwoven medicine, public health, law, anthropology, sociology, and political science, in order to explore the topic of equal access to healthcare for different social groups and in various medical situations.

In the first section of this volume, the authors focus on numerous factors that influence access to healthcare for ethnic, religious and cultural minorities, as well as for individuals with different sexual orientations, or sexual identities. Inequalities in access to, and discrimination of minorities in healthcare have been observed in the literature on the topic and tend to affect members of these vulnerable individuals and groups.<sup>12</sup> Members of various ethnic, religious, or cultural groups experience barriers that include restricted legal entitlements to health services, language barriers, or xenophobia and racism among healthcare professionals.<sup>13</sup> Non-heteronormative per-

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<sup>11</sup> Cultural Competency (Note 9).

<sup>12</sup> Lauralie Richard, John Furler, Konstancja Densley, Jeannie Haggerty, Grant Russell, Jean-Frederic Levesque, Jane Gunn: Equity of access to primary healthcare for vulnerable populations: the IMPACT international online survey of innovations. In: *International Journal for Equity in Health* 15 (2016), <https://doi.org/10.1186/s12939-016-0351-7>.

<sup>13</sup> Megan-Jane Johnstone, Olga Kanitsaki: The Neglect of Racism as an Ethical Issue in Health Care. In: *Journal of Immigrant and Minority Health* 12 (2010), pp. 489–495.

sons, such as lesbians, gays, bisexuals, and transgender persons, experience difficulties in access to the healthcare system as a result of prejudicial and discriminatory behavior and social stigmatization.<sup>14</sup> Therefore, special attention should be paid to the situation of these groups in the healthcare context.

This section begins with Alenka Janko Spreizer's contribution »Social exclusion of Roma from healthcare as a public space: another dimension of antigypsyism?«. Starting with an anthropologic overview of the situation of the Roma minority in Europe and Slovenia, the author describes access to preventive and curative services for Roma in that country. Spreizer argues, that on the one hand, the issue of equality of access to healthcare for Roma needs to be considered concerning their social and economic conditions of living and in the context of their culture. On the other hand, one of the preventive barriers is the lack of healthcare literacy and little knowledge about administrative procedures in healthcare among individuals in this population. Moreover, the results of interviews presented in this article show misconceptions on the side of healthcare professionals and social workers regarding Roma's behaviour and psychological abilities. Improvement of this situation requires, says Spreizer, depart from the traditional misrepresentation of Roma through antigypsyism and promotion of health-educational initiatives.

The examination of the topic of access to healthcare for Roma is continued in Erika Zelko's, Zala Peterka's and Danica Rotar Pavlič's contribution »How challenging is the Slovenian healthcare system for the Roma population?«. Based on interviews conducted with Roma representatives, the authors endeavour to determine attitudes of Roma towards the healthcare system in Slovenia and estimate their challenges in the use of it. The results presented in this contribution show that in general a positive view of the healthcare system dominates among the respondents, at least in comparison to the past views.

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<sup>14</sup> Marcin Orzechowski, Marianne Nowak, Katarzyna Bielińska, Anna Chowaniec, Robert Doričić, Mojca Ramšak, Paweł Łuków, Amir Muzur, Zvonka Zupanič-Slavec, Florian Steger: Social diversity and access to healthcare in Europe: how does European Union's legislation prevent from discrimination in healthcare?. In: BMC Public Health 20, 1399 (2020), <https://doi.org/10.1186/s12889-020-09494-8>; Kathryn Macapagal, Ramona Bhatia, George J. Greene: Differences in Healthcare Access, Use, and Experiences Within a Community Sample of Racially Diverse Lesbian, Gay, Bisexual, Transgender, and Questioning Emerging Adults. In: LGBT Health 3 (2016), pp. 434–442.

Also, improved attitudes and cultural sensitivity of a younger generation of healthcare professionals towards Roma are being acknowledged. However, prejudice, miscommunication, lack of education, and low health literacy still constitute barriers to equal access to healthcare. Health inequalities arise and persist on the basis of multiple mechanisms, including socioeconomic, environmental, and systemic factors.

Blaž Kovač's paper »Roma in Slovenia – a story of disaster« explores the marginalization of the Roma minority in Slovenia. The starting point for his reflections constitutes the decision of the European Court of Human Rights, which dismissed a complaint of two Roma families regarding access to healthcare, appropriate housing, and sanitation as a human right violation. In his contribution, Kovač describes conditions of living and access to healthcare for the Roma minority in Slovenia, stressing an urgent need for the improvement of the situation.

The issue of access to specific healthcare services is the main question of Mateja Lopuh's contribution »Social diversity and access to palliative care for minority groups«. Through interviews conducted with representatives of ethnic minorities in Slovenia, the author sought to gain an insight and understanding of the experiences of patients in palliative care and their proxies. The main obstacles to fair healthcare identified in this research include misunderstanding of the aim of palliative care among the interviewees as well as cultural and language barriers between healthcare professionals providing and their patients. Based on these results, Lopuh states that providers of palliative care should have insight into the ethno-cultural specifics of their patients and the use of interpreters should be more frequent, especially when dealing with important issues of end-of-life. Therefore, the need for palliative care of minority groups' members needs to be identified early in the course of the disease and initial contacts should be made before the symptom burden becomes too high – so the author.

The normative question of access to healthcare for transgender and intersex individuals in Croatian law is in the focus of Ana Pošćić's and Adrijana Martinović's paper »Gender identity and access to healthcare in Croatia – legal framework«. In their contribution, the authors analyze guarantees and standards concerning the access of transgender and intersex persons to healthcare in Croatia. Beginning with an overview of the general legal framework for protection

against discrimination of transgender and intersex persons in Croatia, Pošćić and Martinović then identify and analyse the main legal instruments applicable to this minority. In doing so, they take under consideration a legal framework aimed at collecting the necessary medical documentation for the change of legal gender, and the conditions under which access and financing of specific health services is possible. The authors conclude that although Croatian anti-discrimination legislation explicitly recognizes grounds of gender identity and gender expression, transgender persons in Croatia are better protected than intersex persons when it comes to access to health services and health protection. Furthermore, access to specific health services for transgender and intersex persons is hindered by lack of funding and non-transparent decision-making.

The issues of access to healthcare for migrants and refugees constitute one of the most crucial challenges for healthcare systems in many European countries.<sup>15</sup> Migrants are often deprived of adequate healthcare in their countries of origin. Furthermore, physical and psychological hardships of travel to the countries of destinations can cause various health complications.<sup>16</sup> In addition, barriers related to ethnic, religious, or cultural minorities play here an important role. Lack of legal entitlements, language barriers, administrative obstacles, and instances of racism put migrants in a position of social and healthcare exclusion.<sup>17</sup> Therefore, the provision of rapid and adequate medical health for migrants and refugees should respond to their specific situation and with attention to their particular needs.

This is the focus of the second thematic section of this volume. It opens with the contribution of Mirko Prosen, Sabina Ličen, and Igor Karnjuš entitled »Improving the quality of care for a culturally diverse population: Understanding immigrant women's hospital experiences«. In their paper, the authors present results of interviews with immigrant women hospitalized in a Slovenian obstetrics hospital. This research aims at description of the nature of the health issues

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<sup>15</sup> Bernd Rechel, Philipa Mladovsky, Daniel Ingleby, Johan P. Mackenbach, Martin McKee: Migration and health in an increasingly diverse Europe. In: *Lancet* 381 (2013), pp. 1235–1245.

<sup>16</sup> Julian Bion, Elie Azoulay: The ethics of migration and critical illness. In: *Intensive Care Medicine* 42 (2016), pp. 256–257.

<sup>17</sup> Aniek Woodward, Natasha Howard, Ivan Wolffers: Health and access to care for undocumented migrants living in the European Union: a scoping review. In: *Health Policy and Planning* 29 (2014), pp. 818–830.

for which immigrant women most often seek medical help. At the same time, the authors explore the views of healthcare professionals on the issues of cultural integration in healthcare. The results show the role that healthcare professionals play in recognizing health inequalities and the needs of migrant women arising from their cultural and religious backgrounds. However, so the authors, the challenges of health inequalities are multi-level, and cannot be resolved only in the context of individual patient-healthcare provider relationships. Required are solutions addressed in the context of health policy, which must be more responsive to the needs of migrants entering the healthcare system.

The impact of healthcare systems and policies on occupational and public health safety for health professionals in the situation of healthcare provision for migrants stands in the focus of Alenka Kraigher's and Nuška Čakš Jager's contribution »Occupational risks and protection from infectious diseases in contact with migrants and refugees«. In a review of literature on the topic, Kraigher and Čakš Jager attempt to identify the factors that influence the protection of medical staff and allow the provision of adequate care for patients with migration background. The results lead the authors to the conclusion that systemic response to the challenge is three-fold. First, continuous training for staff involved in migrants' and refugees' healthcare and conscious application of personal protection and vaccination may contribute to better occupational and public health safety. Second, national health systems of the transit and destination countries require policies and health system structural adaptations, which will address in the long-term challenges faced by refugees and migrants. Third, quality care for refugee and migrant groups cannot be addressed by health systems alone but need to be implemented with consideration of social determinants of health such as education, employment, social security, and housing.

The following two contributions provide examples of healthcare for migrants in Slovenia and Germany. Nina Fritz's chapter »Healthcare of Migrants at the Reception Centre Brežice« examines the functioning of emergency medical care for migrants in Slovenia during the migration wave of 2015. Through analysis of documents from this centre, Fritz investigates the scope of medical assistance for migrants. The author concludes that the healthcare system in Slovenia was not prepared for the provision of adequate healthcare for migrants and refugees. The crisis could only be handled through the

involvement of both healthcare providers and volunteers making the arrangements for receiving and treating migrants. When considering healthcare for migrants, it is important to look at healthcare in a broader context, particularly in light of their journey and the circumstances that led them to leave their home country. Necessary is also to account for the possible differences in individual medical conditions, religious beliefs of migrants and refugees, and the language barrier impeding communication in the doctor-patient relationship.

The second contribution, »The refugee guide as an innovative project: Development, implementation, and use at the University Hospital Carl Gustav Carus Dresden«, authored by Robert Bitterlich, Heike Vogelbusch, Stephanie Schierack, Jana Luntz describes a contemporary project named »Refugee Guide«, which has been implemented at a hospital in Germany. This project facilitates refugees' access to healthcare and also benefits medical professionals through various actions aiming at removing language barriers, organization of treatment appointments, and social counselling. As the authors present, the evaluation of this pioneering project by healthcare professionals in this hospital was clearly positive and led to the continuation and expansion of the project.

The third section of this volume focuses on questions of poverty and social vulnerability in the context of access to healthcare. In addition to the issues of ethnicity, culture, sexual orientation and identity, or migration, discrimination in healthcare can be based on several socio-economic characteristics.<sup>18</sup> For example, patients with lower socio-economic status consistently report more discrimination compared to patients with a higher position. This has an impact on both access to primary healthcare clinical decisions such as delaying diagnostic testing or avoidance of referral to specialty care. Moreover, it has been observed that physicians are less likely to perceive patients with lower income as intelligent or independent.<sup>19</sup> Such factors can have a negative effect on various disadvantaged groups of the popula-

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<sup>18</sup> Joshua G. Rivenbark, Mathieu Ichou: Discrimination in healthcare as a barrier to care: experiences of socially disadvantaged populations in France from a nationally representative survey. In: BMC Public Health 20 (2020), <https://doi.org/10.1186/s12889-019-8124-z>.

<sup>19</sup> Nicholas C. Arpey, Anne H. Gaglioti, Marcy E. Rosenbaum: How Socioeconomic Status Affects Patient Perceptions of Health Care: A Qualitative Study. In: Journal of Primary Care & Community Health 8 (2017), pp. 169–175.

tion. They may lead to a lack of attention to their healthcare needs, worse health outcomes, and progressing social marginalization.<sup>20</sup>

The contribution of Ines Gumilar and Erika Zelko »Socio-economic structure of patients and their reasons for visiting pro bono clinics in Slovenia« opens the third section of this volume that concentrates on these issues. The authors present in this chapter the results of research conducted in four pro bono clinics in Slovenia. This investigation aims at determining the socio-economic structure of patients of pro bono clinics in Slovenia and their grounds for pursuing medical assistance in such type of medical institutions. As their results show, pro bono clinics in Slovenia are mostly visited by patients who are vulnerable in a socio-economic sense, i. e. unemployed, without a permanent residence, and those who do not have Slovenian citizenship. Moreover, the clinics provide healthcare service for migrants for who language constitute a barrier in accessing state-administered health services. Gumilar and Zelko conclude that pro bono clinics in Slovenia fulfil an important function with regard to the provision of healthcare for economically and socially excluded groups of society.

This topic is continued in Vida Drame Orožim's contribution »An Outpatient Clinic and Counselling Assistance for People without Health Insurance, Ljubljana, Slovenia«. In this chapter, Orožim describes in detail the organization, structure, and daily work of one pro bono clinic located in Slovenia's capital. The author provides from her own experience a deep insight into the characteristics of people treated in this clinic. The importance of the care provided by the clinic is highlighted by the fact that most of the patients belong to marginalized populations: homeless, people without legal status of nationality in Slovenia, or migrants and refugees. Moreover, in addition to health assistance, the clinic provides social counselling, guidance, and educational activities for highly vulnerable individuals.

In the following paper »The impact of poverty on the position of vulnerable groups in health care – a retrospective study of cases of pregnant women and newborns«, Nada Gosić and Tajana Tomak focus on the multidimensionality and complexity of the phenomena of pov-

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<sup>20</sup> Lise G. M. Hanssens, Jens D. J. Detollenaere, Amelie Van Pottelberge, Stijn Baert, Sara J. T. Willems: Perceived discrimination In Primary Healthcare in Europe: evidence from the cross-sectional QUALICOPC study. In: Health and Social Care in the Community 25 (2016), pp. 641–651.

erty and health. The authors present a review of the literature on the topic, analysing the impact of poverty on the medical condition of pregnant women and newborns as well as normative regulations in international and national documents, which regulate the protection of the right to health for them. Based on the results of their analysis, Gosić and Tomak formulate several recommendations: further expansion of the topic of conjunction of poverty and healthcare in research, development of policies reducing the impact of poverty on health, and implementation of the issue of poverty and health in the curriculum of medical and health faculties.

In the final contribution in this section »Palliative care – the needs of patients with incurable illnesses and their relatives«, Maja Ebert Moltara, Lučka Boltežar, Maja Ivanetič Pantar, and Marjana Bernot explore the topic of palliative care, concentrating on the specific needs of vulnerable patients in different age groups. The authors show that generally, patients in palliative care have common needs, relating to physical, psychosocial, and spiritual care. However, additional individual needs that are specific to various age groups or individual patients, can also be identified. Therefore, the authors reach the conclusion that treatment of palliative patients requires a holistic and individual approach, encompassing individual values, beliefs, and wishes.

As this short overview of individual contributions shows, the topics presented in this volume are as diverse as the issues of social equality and equality of access to healthcare themselves. Such equality is not given; it has evolved in a long history of social and political arrangements. The degree of health equality of vulnerable groups in different European States varies, even though the European Union provides a common normative framework for access to healthcare. Migration, with its all political, social, economic, and human rights consequences has implications for the right to health of migrants and refugees in host countries. Their right to health is often limited by the health capacities in host countries, as well as by other variables, such as the legal status and cultural perceptions of foreigners, which may entail discrimination, language, and cultural barriers. National ethnic minorities, such as Roma, who live in impoverished conditions often cannot afford health insurance, and their health literacy is low, are also inadequately covered by health systems. Migrant and Roma women and children are in an even more vulnerable situation, especially concerning their right to reproductive health. In general, access to



physical, dental, and mental health is limited for vulnerable groups through preventive, curative, and palliative health services. However, individual conditions may greatly impede equality between social groups. The obstacles in the different national health systems presented in this volume should provide an opportunity to make improvements and should serve as an impulse for further considerations of the importance of cultural diversity.