## Florian Steger, Mojca Ramšak, Paweł Łuków, Amir Muzur

## Introduction

Equal access to healthcare for minority groups is one of the major challenges in modern healthcare systems. With regard to various groups that constitute our societies, consideration of their different needs, situations, values, and goals can lead to improvement of their health and contribute to a community, in which individuals can flourish. On the other hand, discrimination in healthcare can lead to further segregation, stigmatization, and exclusion. Race, ethnicity, culture, or sexual orientation in their pluralism are only a few of characteristics of modern societies and have a tremendous impact on participation in medicine and healthcare. They play a role in formulation of healthcare needs, in patient-physician relationship and communication, and in perception of health and illness.<sup>1</sup> The characteristics that constitute diversity can be visible, e.g., race, age or gender, or hidden, e.g., religion, convictions, and sexual orientation, but in many situations they influence the way, in which healthcare is provided. Inadequate legal entitlements, stigmatization, racism, or prejudicial and discriminatory behavior can negatively affect the trust and confidence in healthcare system and lead to negative health outcomes.2

Therefore, reduction of health inequalities for minority and vulnerable groups requires careful consideration. On the one hand, access to healthcare can be influenced by structural factors, as it is acknowledged in in the United Nations' International Covenant on Economic,

<sup>&</sup>lt;sup>1</sup> Tim Peters, Tatjana Grützmann, Walter Bruchhausen, Michael Coors, Fabian Jacobs, Lukas Kaelin, Michael Knipper, Frank Kressing, Gerald Neitzke: Grundsätze zum Umgang mit Interkulturalität in Einrichtungen des Gesundheitswesens. In: Ethik in der Medizin 26 (2014), pp. 65–75.

<sup>&</sup>lt;sup>2</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 (2017), https://doi.org/10.1111/hsc.12353.

Social and Cultural Rights (ICESCR) of 1966. In Article 12 point 1, the ICESCR recognizes »(...) the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.«<sup>3</sup> In accordance with this, point 2 of the Article 12 urges the states that are parties of the Covenant to include steps towards realization of this right, which should include among others: »The creation of conditions which would assure to all medical service and medical attention in the event of sickness.« As recommended by the Committee on Economic, Social and Cultural Rights (CESCR), the goal of the highest attainable standard of health, public health, healthcare facilities, goods and services, as well as programs should contain four elements: availability, accessibility, acceptability, and quality. 4 In the context of non-discrimination, especially the requirements of accessibility and acceptability gain important role. First, health facilities, goods and services should be accessible to »everyone without discrimination«, especially to the most vulnerable or marginalized sections of the population. Second, the dimension of acceptability relates to a respect for medical ethics and cultural background. In particular, all health facilities, goods and services must be: »(...) culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements.« According to the CESCR, the national states have a continuing obligation towards the full realization of the Article 12 of the ICESCR. This obligation is threefold, it includes duties to respect, protect, and fulfill the human right to healthcare. States' duty to respect the right to health concerns refraining from denying or limiting equal access to preventive, curative, and palliative health services for all persons, including among others minorities, asylum-seekers, and illegal immigrants. The duty to protect encompasses an obligation to adopt legislation ensuring equal access to health care. The States are also required to facilitate access to healthcare for individuals and communities, to provide specific rights for the realization of the right to health, and to promote the right to health through creation, maintaining, and restoration of the

<sup>&</sup>lt;sup>3</sup> United Nations: International Covenant on Economic, Social and Cultural Rights. Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966. https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx (accessed on 7.2.2023).

<sup>&</sup>lt;sup>4</sup> United Nations' Committee on Economic, Social and Cultural Rights: General comment no. 14 (2000): The right to the highest attainable standard of health. (11.8.2000). https://digitallibrary.un.org/record/425041 (accessed on 7.2.2023).

health of the population. This last point contains a specific provision concerning diversity-oriented health services. Namely, States should ensure: »(...) that health services are culturally appropriate and that healthcare staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups.«

This last point touches on ethical dimension of access to health-care. It reflects on individual behaviors of all involved in provision of medical care. Equality of access to healthcare involves the ethical responsibility to minimize differences in providing the best healthcare for individual patients without discerning the social minority groups to which they belong. This should occur in congruence with the medico-ethical principles of autonomy, beneficence, non-maleficence and justice<sup>5</sup> and based on the fact, that all humans are bearers of human dignity. In this context, diversity competence becomes one of the central issues of the modern healthcare services. It involves a commitment to appropriate policies and practices to improve the capacity of healthcare organizations and healthcare professionals in the provision of quality healthcare for diverse populations. It aims at improvement of patients' satisfaction and efficiency in provision of medical care, with the overall goal of better health outcomes.

This volume includes twelve contributions from various fields gathered under the common topic of access to healthcare. It is divided into three sections: vulnerable groups, minorities, and healthcare professionals. In their contributions, twenty authors explore the topic of equal access to healthcare from various perspectives: of patients from vulnerable and minority groups, their relatives as well as different medical professions. The chapters of this book present impulses for a debate on one of the central questions of healthcare nowadays: How can participation in modern medicine be provided for all? As is clear from the following contributions, the answer is not straightforward and requires a multifaceted and interdisciplinary consideration of various viewpoints, concerns, and individual circumstances. The following passages shortly describe individual chapters in this volume.

<sup>&</sup>lt;sup>5</sup> Tom L. Beauchamp, James F. Childress: Principles of Biomedical Ethics. 8<sup>th</sup> Edition. New York, Oxford 2019.

<sup>&</sup>lt;sup>6</sup> Cindy Brach, Irene Fraserirector: Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model. In: Medical Care Research and Review 57 (2000), pp. 181–217.

In the first section of the volume, the authors examine different factors that influence access to healthcare for vulnerable groups. Belonging to such a group can constitute a relevant obstacle in equal participation in medicine and healthcare services. Vulnerable groups can be especially susceptible to discrimination because of structural determinants such as inadequate provision of healthcare services but also because of limited awareness of healthcare professionals to their particular needs. Moreover, lack of sensitivity to the distinct situation of vulnerable groups, such as women, minors, or individuals from gender and sexual minorities can lead to depersonalizing or paternalistic treatment. Therefore, in focus of the contributions gathered in this section stand questions of special attention to the position of vulnerable groups in the healthcare system.

Discussion about challenges in accessing healthcare first requires a scrutiny of questions related to individual autonomy of patients entering the patient-healthcare professional relationship. Hence, this section opens with Julia Allessandra Harzheim's contribution »The role of Patient Autonomy and Informed Consent for equal access to healthcare: A conceptual inquiry of contemporary bioethical debate«. The author explores various normative dimensions of the concept of autonomy, its development, and links to other conceptions across disciplines, countries and scientific inquiries. Basing her analysis on the results of literature review, Harzheim argues that the contemporary debate on this topic is dominated by the understanding of patient autonomy and informed consent, which mostly originate from Anglo-American discourse in social sciences. This notion is contrasted with the concept of autonomy presented in Kantian philosophy. The author concludes that growing attention to questions of equality and discrimination in different scientific disciplines drives interdisciplinary and pragmatic approach as well as various measures to address and resolve these issues. However, this development also presents conceptual challenges, such as introduction of a new definition of vulnerable and minority groups. Therefore, Harzheim holds that re-assessing the concept of autonomy and its links to informed consent in the contexts of vulnerability and social diversity is crucial for any further scientific pursuit in this topic.

 $<sup>^7\,</sup>$  Erika Gathron: Vulnerability in health care: A concept analysis. In: Creative Nursing 25 (2019), pp. 284–291.

<sup>&</sup>lt;sup>8</sup> David B. Waisel: Vulnerable populations in healthcare. In: Current Opinions in Anesthesiology 26 (2013), pp. 186–192.

After this analysis of conceptual questions connected to issues of autonomy and access to healthcare for vulnerable and minority groups, the following authors in this section focus on challenges and opportunities for particular vulnerable groups: women, children, and individuals of sexual and gender minorities. Nika Pavlović's contribution »Disparities in women's access to reproductive healthcare« analyses the question of women's access to reproductive healthcare in Croatia, Germany, Poland and Slovenia. Starting with an observation on the influence of various factors on women's health and description of the differences in health systems in these four countries, the author focuses her analysis on challenges and initiatives that aim to reduce disparities in access to healthcare for women in each individual country. The analysis shows similar challenges in all countries under analysis. Issues of pregnancy termination, contraception and access to reproductive healthcare for women form minority groups are observable in all four countries; however, with specific inclinations in particular countries. These specificities result in various strategies towards issues such as gaps in access to healthcare for vulnerable groups, in maternal and newborn healthcare, or in meeting healthcare needs of women with migration or minority backgrounds. In the final section of this chapter, Pavlović turns her attention to the question of access to reproductive medicine in times of COVID-19 pandemic, which in many cases compromised access to reproductive healthcare, especially for vulnerable groups; it also, to various extent depending on the country, contributed to expanding telemedicine, e.g., as a tool used in medical consultations. The author concludes that reproductive health education as well as development of professional normative guidelines are necessary for improvement of the situation.

The issue of access to healthcare for vulnerable groups, this time from the perspective of minors, is continued in Gordana Šimunković and Ivana Borić's contribution »Exercise of children's participatory rights in the healthcare system of the Republic of Croatia«. The authors' focal point in this paper lies on the issue of children's vulnerability and their protection and participation. Opening with a theoretical analysis of the concept of children's vulnerability, the authors then move to an analysis of participatory rights of children in the Croatian healthcare system. This analysis starts with an overview of international and national policy documents regarding child participation in the healthcare system, after which the authors move to the question of how a balance between protection of children and

their participation in healthcare can be achieved. On this ground, the authors present the results of an international and national study, on the ground of which they identify components for facilitation of children's participation. In their concluding remarks, Šimunković and Borić postulate to further invest in the promotion and education of children's rights, development of guidelines for the participation of children in the healthcare system which will strengthen the connection between policy and practice, and further exploration of the topic in research.

Although there has been considerable progress regarding the acceptance and protection of individuals of sexual and gender minority, they still suffer from substantial discrimination and disparities regarding their access to healthcare. Therefore, in their contribution, Ann Kristin Augst and Annika Spahn examine LGBATIQ patient's experiences in the German healthcare system. Based on group discussions and interviews conducted with queer patients, the authors endeavor to determine the barriers for LGBATIQ individuals in access to healthcare. Moreover, the authors attempt to identify how discriminatory experiences shape the health of LGBATIQ people in Germany. The chapter begins with an overview of the concept of heteronormativity as a theoretical framework and in relation to socio-political and regulations and individual patient-doctor interactions in Germany. Next, Augst and Spahn present results of their research, according to which stigma and discrimination lead to minority stress, which in turn impacts health of affected individuals. Additionally, actual, or even anticipated, discrimination leads to avoidance of seeking of medical attention, which, correspondingly, impacts health of LGBATIQ individuals. Furthermore, deficient awareness on the side of healthcare professionals concerning specific healthcare needs of this group can lead to inappropriate care or even to treatment errors. In order to improve healthcare of the minority group under consideration, the authors propose in their concluding remarks an increased attention to, and reflection on specific needs of queer individuals, especially in situation of medical encounters with healthcare professionals.

Individual experiences of representatives of vulnerable groups can provide important insights into the limits in provision of health-care services for them but also into consequences for personal life. In the chapter entitled »Becoming a parent as a lesbian in Poland: an autoethnographic narrative« Marta Lewandowska presents a personal narrative about the perspective of homosexual individuals

seeking to have a child in Poland. Based on her personal experience, Lewandowska explores individual ordeal on the way to motherhood - from the decision to become a parent, through exploring clinically supported reproduction options in Poland, to the experiences of pregnancy and birth. The personal story of the author provides a framework for an account of legal and social homophobia, stigma, and discrimination. The author's personal story provides a basis for normative and interpersonal recommendations. Without structural and systemic changes to the regulations and medical practice in Poland, Lewandowska concludes, improvement of the situation of homosexual »parents to be« is impossible. These changes should encompass modifications of the legal status of homosexual individuals in Poland and improvement of access to clinical reproduction methods. Moreover, there is a pressing need for support for homosexual persons; through assistance provided to them, through groundwork on discriminatory perception of this group that is prevailing in the society, and through education about experiences of homosexual persons in Poland, not only for healthcare personnel but also for whole society.

The question of access to healthcare for representatives of ethnic, national, and religious minorities stands in the focus of the second section of this volume. This issue arises often with regard to the subject of migration and healthcare. People with a migration background often have a lower socioeconomic status, work in health-damaging conditions, are unemployed, or live in unfavorable conditions. However, religious or ethnic minorities also often face unfavorable situations in healthcare environment due to language and cultural barriers or their beliefs. This can have a deteriorating result on the health situation of individuals from these groups and is especially threatening if it coincides with structural barriers in accessing healthcare.

With regard to these issues, in the contribution »Provision of healthcare for culturally diverse populations: Insights from a qualitative study on dementia care with the members of the Turkish immigrant community in Germany« Zümrüt Alpinar-Sencan examines the situation of first-generation migrants in Germany in accessing healthcare. Through interviews conducted with caregivers and relatives of people with dementia of Turkish descent living in Germany,

<sup>&</sup>lt;sup>9</sup> Bernd Rechel, Philipa Mladovsky, David Ingleby, Johan P. Mackenbach, Martin McKee: Migration and health in an increasingly diverse Europe. In: Lancet 381 (2013), pp. 1235–1245.

the author analyses their experiences on dementia care and expectations for counseling. After opening with remarks on provision of dementia care for culturally diverse populations and on culture's role in healthcare ethics, Alpinar-Sencan moves to presentation of the results of qualitative interviews. These highlight the needs of migrant groups in healthcare situations: from information about disease and its management, through social support, to increased sensitivity to cultural differences of the patients from the healthcare professionals. The interviewees' testimonies distinctly show the role of culture in shaping health-related phenomena. Moreover, apparent become the aspects of the impact of migrant life on the initiation of dementia and the importance of family care. Based on the results of the interviews, Alpinar-Sencan underlines the pressing need for culturally sensitive healthcare, which should contribute to overcoming language barriers and improvement of patient-doctor relationship. Moreover, a migration background can cause and reinforce perception of discrimination in healthcare, which can in consequence lead to worse healthcare outcomes. Therefore, the author argues, there is a moral obligation of culturally responsive healthcare. However, in adopting such an approach, individual needs, perceptions, and identities of patients cannot be ignored.

Considerations of influence of religious beliefs on provision of healthcare, on the example of one particular religious group, are in the focus of Dean Markić and Lada Zibar's contribution »Kidney transplantation in Jehovah's Witnesses - the Croatian perspective«. Based on the specific examples of patients treated at the University Hospital Rijeka in Croatia, the authors describe medico-legal and ethical dilemmas revolving around the questions of patient's autonomy and provision of medical care. Especially in the case or religious convictions, like in the case of Jehovah's Witnesses, the medico-ethical principles of autonomy, beneficence, non-maleficence, and social justice present healthcare professionals with challenges. Markić and Zibar present in their chapter the medical as well as legal and ethical perspective on this issue. The authors point out, that in such specific situations, as the ones presented in their chapter, there is a need for clear-cut guidelines prepared with participation of all stakeholders: national legislators, professional medical societies, and patients' associations. Only through involvement of all interested parties and through inclusion of patients' will and choice, as well as the rights and

beliefs of healthcare professionals, every patient's access to the best possible healthcare can be offered and guaranteed.

In the following contribution entitled, »Health status and access to the healthcare system of members of the Roma national minority in the Republic of Croatia«, Suzana Kunac and Aleksandar Racz turn their attention to the challenges experienced by a particular minority group, Roma people, in accessing healthcare in Croatia. In their chapter, the authors aim to systematize and analyze the data on the status, access, and discrimination of Roma. They also attempt to deepen the existing knowledge regarding the approach to health of Roma minority in this country. Analyzing the current situation, the authors state that the health of this minority group is influenced by their living conditions, insufficient nutrition, and poverty. This leads to development of chronic non-communicable diseases at a much younger age than in the general population in Croatia, However, as Kunac and Racz observe, a considerable number of Roma individuals report discrimination in healthcare. In order to counteract discrimination of this group, the authors argue for systematic monitoring of data on the use of healthcare, as well as on discrimination, challenges, and obstacles to the use of health services with consideration to the ethnic groups, to which the patients belong. Such actions, supported by research on this topic, could contribute to elimination of systemic barriers in access to healthcare for Roma individuals and allow members of this group access to healthcare on the same conditions as it is provided for the majority of the Croatian population.

In the third thematic section of this volume, the authors focus on the questions of social diversity and access to healthcare from the perspective of different professional groups: medical doctors, nurses, and social healthcare workers. Recognition and understanding of diversity and equality is essential for the provision of quality healthcare. However, in many situations, lacking education about implications of ethnicity, race, culture, belief, or sexual orientation leads to discrimination and diminished healthcare outcomes. Individual discrimination can occur on the level of personal encounters, i.e. between a healthcare professional and an individual patient. Obstacles

<sup>&</sup>lt;sup>10</sup> Lesley Baillie, Milika Matiti: Dignity, equality and diversity: an exploration of how discriminatory behavior of healthcare workers affects patient dignity. In: Diversity and Equality in Health and Care 10 (2018), pp. 5–12.

in such individual encounters have various contexts, e.g. they can stem from factors such as language barriers, different concepts of health and disease, or the presence of racism. <sup>11</sup> In their contributions, the authors in this section present how healthcare professionals view diversity and access to healthcare, what challenges in this regard they observe in their countries and their daily practice, and what solutions they offer.

The chapter »Diversity-sensitive healthcare delivery across Poland's clinical landscapes« by Ewa Nowak, Anna-Maria Barciszewska, Karolina Napiwodzka focuses on the perspective of Polish healthcare practitioners in dealing with patients of diverse national, ethnic and cultural backgrounds. In the center of their investigation stands the question of how health providers rate pro-diversity knowledge and competencies of fellow clinicians in ensuring equitable access to health services for minority groups. In order to answer this question, the authors conducted a survey among Polish clinicians employed in hospitals, medical practices, and non-public units. The results show that respondents generally assessed levels of knowledge, awareness, and competence of their fellow clinicians as medium-high to low. Highest scores received clinicians' competence to identify and distinguish diverse sociocultural identities, awareness of stereotypes circulating among clinicians about patients and vice versa, and attitudes toward factors contributing to health disparities. These opinions are not significantly dependent on age, gender, professional specialties, or length of professional service. However, respondents employed in hospitals or clinics rated diversity related knowledge in their collaborators higher than respondents employed in other healthcare units. Main barriers to socio-culturally competent healthcare, according to the respondents, are lack of time, lack of resources and awareness, and prejudices. According to authors, these results, are to be traced to lack of education in the area of diversity-sensitive healthcare and low professional internationalization. Therefore, the question arises whether Polish healthcare sector is sufficiently equipped to deal with the issue of equal access to healthcare for patients from diverse minority groups.

The perspective of healthcare professionals with regard to care for patients with culturally diverse background is further explored in Bojana Filej, Mojca Poredoš and Boris Miha Kaučičs contribu-

<sup>&</sup>lt;sup>11</sup> Nancy Krieger: Discrimination and health inequities. International Journal of Health Services 44 (2014), pp. 643–710.

tion »Educational needs of nurses in intensive therapy units to improve attitudes towards interculturally diverse patients in Slovenia«. The focus of the research presented in this chapter is the issue of cultural competency in intensive care units in Slovenia. The authors begin with presentation of the importance of cultural competencies in healthcare environment. Such competencies are crucial for provision of culturally congruent care through better communication with patients and their relatives and respect of patients' beliefs and values. As cultural diversity is one of the major challenges for modern healthcare, integration of specific training, which is aimed at improvement of cultural competencies is central in patient-oriented healthcare. Against this background, the authors ask the question about the need for the education of nurses in intensive care units with regard to their attitudes towards culturally diverse patients. In order to answer this question, the authors gathered qualitative data from 98 healthcare providers from intensive care units in Slovenia. The results show that participants expressed a relatively strong need for education, especially in group of nurses who perceive themselves as sympathetic towards interculturally diverse patients. Based on these results, the authors postulate implementation of educational contents for self-education to improve the cultural knowledge, skills, and competencies of nurses in the ICU, which can consecutively reduce inequalities in treatment for culturally diverse patients.

Beside lack of sufficient education about implications of social diversity on the question of access to healthcare, communication barriers can be a major obstacle for provision of quality healthcare. Therefore, in their contribution entitled »The importance of improving education of healthcare professionals on communication with minorities - experience with Roma in the Croatian healthcare system«, Sanja Pleština and Sandra Karabatić explore this issue by focusing on miscommunication with family members of a Roma patient, which led to an emotional shock. The authors analyze how communication barriers can be triggered by emotions, stereotypes, and conflicts of values and beliefs. Based on the results of a meeting with representatives of the Council of Roma Minorities of the City of Zagreb, the authors present strategies for better understanding and communication with ethnic and cultural minority groups. The authors especially highlight the need for awareness of individual patient's background, culture, and values. Perception of these unique features

builds trust in the patient-physician relationship and improves care in the medical setting.

In healthcare encounters, not only medical doctors and nurses play an important role. Other healthcare professions contribute to the provision of quality medical care for various social groups. Challenges of work with patients from culturally diverse groups from the perspective of social workers are presented in Vanja Branica and Ivana Mošić Pražetina's chapter »Improving access to healthcare for minority groups: qualitative study with social workers in Croatia«. Through qualitative research conducted in focus groups the authors had access to the experiences of this professional group working with culturally diverse patients and to examples of good practice. Among main obstacles in provision of quality healthcare for minority groups, the authors mention communication barriers, administrative procedures, and lack of time for attention to patients' issues. The respondents participating in the research acknowledged the need for improvement of the situation, which could be achieved through increased effort in administrative tasks and procedures, improved cooperation within and between institutions and systems, advocacy for patients' rights and improved communication with patients. The goal of better access to healthcare services, so conclude the authors, should be achieved through inclusion of the concept of cultural diversity in educational programs for social workers and healthcare providers throughout their professional career. Moreover, development of work protocols within a hospital and between hospital social workers, social care system, police, and other state agencies could improve provision of quality healthcare for patients from minority groups.

The contributions to this book make it clear that the challenge of providing equal access to healthcare for minority groups is not a marginal matter but stands in the very center of medicine and healthcare nowadays. The chapters show that attention to this question is important from the perspective of all stakeholders in the healthcare system: from patients from minority groups to healthcare professionals, who include physicians, nurses, social workers, and other professions involved in healthcare environment. Individual ethical reflection on this challenge is important. It can start with realization of individual shortcomings in diversity competency and ways to improve it, through perception of different backgrounds, values, and goals of all involved in the healthcare setting, to better communication, not only through reducing language barriers but also through sharing

ideas, thoughts, and feelings. However, this is not enough. The amelioration of the situation requires a systemic approach. Provision of education in cultural competency, enhancement of patients' rights, development of joint strategies against discrimination in healthcare on international and national levels, and further research on the topic, involving both patients and healthcare professionals, are only few but important steps towards the goal of socially inclusive healthcare.