Equal Access to Healthcare in Europe

edited by
Paweł Łuków
Amir Muzur
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Introduction

Cultural, ethnic, lifestyle and other forms of social diversity are sometimes perceived as a burden and source of difficulty in the daily functioning of societies. Equality and equal access to various benefits and services are therefore seen as measures whose aim is to offset the unwelcome effects of diversity. However, one needs to be reminded that diversity is not a challenge on its own. When it is a source of social difficulties, it is predominantly due to human actions and omissions. If anyone suffers because of being different in any way, it is not the difference that is responsible for the suffering. It is actions and omissions as well as regulatory and institutional arrangements that are responsible for the suffering and for diversity becoming a problematic issue. In a favourable environment, diversity is a social asset and a source of cultural richness in societies that recognise and value its potential.

This volume grows out of the belief that diversity needs recognition and support from a favourable social environment. More precisely, the different members of diverse societies need recognition and support. This monograph is intended to provide a comparative perspective on the challenges faced in selected European countries (Croatia, Germany, Poland, Slovenia and the UK) with regard to equal access to healthcare and ways of handling them. The authors of the chapters comprising this volume, each within their specialty and in their own way, attempt to identify the different forms and dimensions in which we can be different and the barriers to our flourishing in, and with our differences. They were invited to two conferences organised by the research consortium *Healthcare As a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe* funded by the Humanities in the European Research Area (HERA) under the HERA Public Spaces: Culture and Integration in Europe Programme (Hera.2.029) and by the national funding agencies: Academy of Sciences and Arts (Croatia), Federal Ministry of Education and Research (Germany), National Science Centre (Poland), and Ministry of Education, Science and Sport (Slovenia). The conferences took place in Rijeka (5–6 September 2019) and in Warsaw (4–5 March 2020). The consortium is composed of four teams: Project Leader of the whole European project and Principal Investigator of the German Research Group at the Institute of the History, Philosophy and Ethics of Medicine of the

University of Ulm is Prof. Dr. Florian Steger. Prof. Dr. Amir Muzur is the Principal Investigator of the Croatian Research Group at the Department of Social Sciences and Medical Humanities at the Faculty of Medicine of the University of Rijeka. Principal Investigator of the Polish Research Group at the Centre for Bioethics and Biolaw at the University of Warsaw is Prof. Dr. Paweł Łuków. Principal Investigator of the Slovenian Research Group at the Institute for the History of Medicine at the Faculty of Medicine of the University of Ljubljana is Prof. Dr. Zvonka Zupanič-Slavec. Participating in the project are post-doctoral researchers and graduate students from all the four countries: Dr. Marianne Nowak and Dr. Marcin Orzechowski (German team); Dr. Robert Doričić and Ivana Tutić-Grokša (Croatian team); Dr. Katarzyna Bielińska and Anna Chowaniec (Polish team); Prof. Dr. Mojca Ramšak (Slovenian team).

To be recognised and acknowledged, various forms and dimensions of the human ways of being and living must be appropriately conceptualised. Conceptualisation is never free from context. The particular milieu and its cultural, regulatory and organisational components shape the way we see differences and the extent to which we are capable of appreciating their potential and recognising barriers to it. The conceptualisations to be found in this volume are shaped by four interacting contexts.

The first and most general context is that of healthcare. Health is one of the most important assets in human life. Access to healthcare services, which are of necessity scarce, determines how well one's life can proceed. It opens prospects for a good life; its absence deprives us of some of the most basic opportunities. Equal access to healthcare is a precondition for a fair share in a good life; unequal access to healthcare is an injustice with a great potential to generate further injustices such as social rejection, stigmatisation and discrimination. Equal access to healthcare is one of central forms of institutionalisation of respect for human dignity and rights in modern society; unequal access to healthcare is proof of social divisions which create inequalities and disrespect for individuals.

The second context is that of the European values and ideals which are enshrined in the European law, institutions, practices and the political culture, which is still in the process of development. This context provides the most general normative framework for thinking about diversity and equal access to social services such as healthcare. Some of them are to be found in the European law, others in political action, still others find expression in social and political activism and involvement. This context also shows differences between Member State societies and their specific problems related to diversity and equal treatment.

The third context is provided by the national laws in each of the four countries represented by the members of our research consortium: Croatia, Germany, Poland and Slovenia. Different laws, histories and social structures generate different kinds of problems, which sometimes are not easily comprehensible by others. The specific ways in which equal access to healthcare issues are conceptualised in these four countries reflect their histories and cultural backgrounds, but also their shared commitment to the value of diversity.

The fourth conceptual context is provided by the expertise of each of the contributing authors. They discuss diversity, the ways to understand it and the various forms of barriers to its recognition and appreciation from the points of view of ideologies, regulations, social and political history, training of medical professionals, cultural competence, architectural solutions and many others. The authors focus on the situation of, among others, non-heteronormative persons, members of ethnic minorities, migrants, psychiatric patients.

In the chapter entitled: “Legal protection of the elderly from the Croatian perspective: Why do we need a UN convention on rights of the elderly?”, Sunčana Roksandić Vidlička and Stjepan Šikoronja analyse whether, from the perspective of the Republic of Croatia, there is a need to support the drafting and adoption of the Convention for the Protection of the Rights of the Elderly under the auspices of the United Nations. The chapter presents the current state of regulations concerning special rights of elderly persons at international, European, and national levels. The authors also refer to the relevant rulings of the European Court of Human Rights (ECHR) in its presentation of the main problems faced by the elderly, especially those with mental disorders, in the Republic of Croatia. Based on the analysis of the existing situation, the authors suggest which rights could or should contain the UN Convention on the Rights of the Elderly.

The chapter entitled “Back to the future: Socialist legacy and recent developments in the Croatian healthcare system” was authored by Hrvoje Jurić. While providing a broader historical context, Jurić analyses the debate between conservative and liberal views and parties with respect to such issues as abortion or commercialisation and privatisation of healthcare. In his concluding remarks, the author asks what happened to the legacies of Andrija Štampar and the Yugoslav socialist system of healthcare. Jurić suggests an investigation into the ideology and a radical reform of the very conditions of politics in the name of both individual and common good.

Vanessa Marie Zeeb authored the chapter entitled: “Healthcare for persons seeking international protection in Germany – Psychiatric and psychotherapeutic care”. Zeeb compares the German Asylum Seekers Benefits Act (AsylbLG) to a “melting pot“ for all persons seeking protection, considering particularly the entitlement conditions for healthcare (paragraphs 4 and 6 AsylbLG) to be very restrictive. Having assumed that the length of stay of asylum seekers would be short, and that for this reason long-term treatment would not be appropriate, the German government, according to the author, does not include persons seeking international protection into the regular social assistance scheme. Detecting a wide gap between the services of the this scheme (SGB V [Social Security Code No. 5: Statutory Health Insurance]) and the services of the AsylbLG, Zeeb strongly criticises German legislation and concludes that a broad range of EU law requirements are promising and can contribute to better provision of healthcare to refugees.

In the chapter "Navigating the void: the qualitative study of patients with rare inborn errors of metabolism perception of healthcare regulations", Katarzyna Ewa Król focuses on rare diseases. She discusses the data obtained in a study examining the daily experiences of people with rare metabolic disorders and their family members in Poland. Król concludes that lack of legal regulations regarding this vulnerable group, resulting in inequality in the access to healthcare, demands action of patient advocacy organisations.

Anna Hucko explains the dilemmas of the role of healthcare coordinator as a management function in primary healthcare in Poland. The competencies of a coordinator required by Polish legislation are threefold: the ability to promote patients' entitlement to the best quality of care and to empower patients to become active participants in their health; the ability to quickly establish a relationship with patients and their family members in an empathetic and sensitive manner which incorporates the patients' perceived and stated culture; the ability to effectively organise an interprofessional team which would include providers, patients and family members. The help which family physicians need and which could improve patient access to healthcare is a trained, independent secretary who could perform administrative tasks.

Katja Triller Vrtovec writes about equal access to healthcare for the low-income population in Slovenia. In her opinion, suboptimal access to healthcare is not caused by financial reasons or inputs in the healthcare system, but by long waiting times. Her analysis shows that abolishing voluntary health insurance and replacing it with compulsory insurance would only partially improve access to healthcare for the low-income population. Moreover, she predicts that the elimination of voluntary health insurance would worsen timely access to healthcare for all segments of the population, regardless of income. Since the unmet needs for healthcare services will increase sharply after the COVID-19 pandemic, a reform of the healthcare system must be the government's priority.

Jasna Murgel presents the legal remedies for victims of ethnic discrimination in Slovene and international law. She discusses key international documents, complaint procedures, the Court of Human Rights, Slovene legislation, procedures for the protection of the patient's rights, the Human Rights Ombudsman, the constitutional complaint and the Slovene case law. She concludes that despite there being necessary legal provisions in place in international and national law, the system as a whole is not efficient enough in practice. Discrimination based on ethnic origin in healthcare exists just as it does in other areas of social life.

A team of researchers from Slovenia, Mirko Prosen, Igor Karnjuš and Sabina Ličen, analyse the barriers in access to healthcare services in clinical obstetrics and gynaecology using the example of migrant women. The authors point out that it is the lack of cultural awareness in host societies stemming from lack of knowledge, ethnocentrism, stereotyping or prejudice which are responsible for the violations of human rights. By exploring the experiences and perceived barriers of health workers in caring for migrant women in institutional settings, Prosen, Karnjuš and Ličen emphasise the importance of cultural competency and mainstreaming the issue of cultural diversity in health facilities. Such additional training will give health workers the necessary skills needed for the provision of culturally sensitive healthcare.

In the chapter "Access to healthcare from the aspect of the Human Rights Ombudsman of the Republic of Slovenia", Simona Mlinar presents the work of the human rights ombudsperson dealing with challenges in exercising the right to equal access to healthcare in Slovenia. In four case studies, Mlinar looks into the Slovenian human rights ombudsperson's practice. As the first step, she explains the legal basis for the right to healthcare in Slovenia and for the possible scope of complaints by individuals. The following different cases deal with challenges for different minority groups – such as Roma, migrants or international protection applicants – in the healthcare system. These cases show the legal insufficiency and rigidness in the Slovenian healthcare system, which leads to unequal access to healthcare.

In the chapter "Ethical aspects of intercultural communication in the context of access to healthcare", Ilhan Ilkilic highlights the importance of communication for a well-functioning healthcare system. Communication is a key aspect in the relationship between a doctor and a patient, which means great challenges when the patient does not speak the native language of the country where they undergo medical examination. A common solution to these language barriers is the involvement of semi-professional interpreters. Ilkilic focuses on the ethical problems that may occur in such a context if interpreters do not translate well due to insufficient language skills or even intentionally provide inaccurate translation. Various examples are discussed and analysed to identify the interpreter's required skills in intercultural treatment situations.

The chapter "A place of safety in crisis: The spatial examination of mental health crisis care facility in the UK" by William Wang and Jacek Kornak discuss the topic of healthcare as a public space from an architectural point of view. This approach recognises the direct impact of the design of clinical space on patients and their recovery. The authors explain how clinical space in a mental health crisis care facility can be constructed and designed in a patient-centred way. The aim of such architectural considerations is to obtain an environment which not only secures physical safety, but also can stimulate therapeutic effects.

The findings result in the recommendations for design guidelines for Health-Based Places of Safety.

These contributions show that adequate conceptualisation of diversity and the barriers to meeting the needs of members of various minorities are the preconditions for addressing their needs. They also show that their equal access to healthcare is only possible if the society as a whole and its members individually are open to differences. To be treated equally, we need to be recognised both as belonging together and as being different. We also need to appreciate the potential of differences. Only then can we flourish as individuals, societies, countries and as Europeans.

Acknowledgments

We would like to thank the persons and institutions who made our work on the topics of diversity and equal access to healthcare meaningful and enjoyable. We would like to thank the honorary sponsors of our Warsaw conference: Commissioner for Human Rights of the Republic of Poland and the Copernicus Science Centre in Warsaw. We also thank the Commissioner for Human Rights, Adam Bodnar, for opening the Warsaw event.

Paweł Łuków, Amir Muzur, Mojca Ramšak, Florian Steger

Sunčana Roksandić, Stjepan Šikoronja

Legal protection of the elderly: Why do we need a UN convention on the rights of the elderly?[1]

1. Introduction

The aging of the population is the most significant demographic trend not only in the Republic of Croatia, but also throughout Europe. It is a trend that has many consequences.[2] The aging of the population is therefore reflected in the immigration policies of the Member States of the European Union (hereinafter: EU) due to an increasingly unfavourable ratio of labour force and retired population. This trend is not just recent. Already in 2008, the share of the European population in the total world population decreased from 22% in 1950 to only 12%.[3]

Unlike some other vulnerable social groups, the rights of the elderly are not specially codified at international level. A special United Nations (hereinafter: UN) Convention is still missing. Unlike the elderly, children[4] and people

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[1] The Croatian version of this paper was prepared at the invitation of Professor Velinka Grozdanić, Project Manager of the Croatia Science Foundation Project IP-11-2013-2287 "Legal Status and Real Position of People with Mental Difficulties – Interdisciplinary Approach and European Perspectives". The paper was initially published in Croatian, under the title: "Pravna zaštita starijih osoba, osobito s duševnim smetnjama, iz hrvatske perspektive: Zašto nam je potrebna Konvencija UN-a o pravima starijih osoba". *Zbornik Pravnog fakulteta Sveučilišta u Rijeci* [Collected papers of the Law Faculty of the University of Rijeka] 38 (2017), pp. 1101–1129. Available at: https://hrcak.srce.hr/193715. For assistance in translation, gratitude goes to student assistants at the Department of Criminal Law: Luka Švić, Lara Bogdanović and Darja Drempetić, Faculty of Law, University of Zagreb.

[2] Ivana Rešetar Čulo, "Zaštita prava starijih osoba u Europi: Trenutno stanje, nedostaci i izazovi". *Pravni vjesnik* 30 (2014), p. 121, citing *Active ageing and solidarity between generations, A statistical portrait of the European Union 2012*. Luxembourg 2011, p. 7.

[3] Rešetar Čulo, "Zaštita prava...", op. cit., p. 119, citing United Nations, Department of Economic and Social Affairs, *Regional Dimensions of the Ageing Situation*. New York 2008, pp. 119.

[4] Convention on the Rights of the Child. United Nations General Assembly. Available at: https://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 27.10.2020).

with disabilities[5] have their own convention at the UN level. This explicitly acknowledges that the documents which regulate general human rights are not fully adequate to protect the rights and interests of vulnerable groups in society. Despite repeated requests for its enactment, the elderly are still waiting for their Convention. The authors argue that protection of rights and interests of the elderly has so far been insufficiently recognised, neither by the creators of policy nor by the legal community, not only in the Republic of Croatia, but also worldwide.[6]

According to statistics, the average life expectancy of a person in the Republic of Croatia was 77.3 years in 2015.[7] Only 50 years earlier, in 1965, it was 66.5 years.[8] The situation is similar in other EU Member States.[9] Consequently, combined with a negative rate of natural increase,[10] the share of the elderly in the general population in the Republic of Croatia in 2016 was 19.2%.[11] Between the two censuses (2001 and 2011), the number of elderly people in the Republic of Croatia (hereinafter: RH) increased by 65,123 people. Thus, in 2011 there were 758,663 persons over the age of 65 in the RH,[12] as compared to 693,540 in 2001.[13] In 2011, there were 652,428 children under the age of 15 in the general population of the RH. Thus, in Croatia, one in six inhabitants is older than 65, there are 11.6 people over the age of 65 per every 10 children under the age of 15. According to the UN's demographic projection, the share of elderly people in Croatia in 2050 will be as high as 46.9%, of whom

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[5] Convention on the Rights of Persons with Disabilities. United Nations General Assembly. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 27.10.2020).

[6] For example, a search for "rights of the elderly" in English in Google Scholar yielded 223,000,000 results, while a search for "rights of the child" yielded 5,890,000,000 results (22.09.2019).

[7] World Bank, *Life expectancy at birth*. Available at: https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=HR (accessed 27.10.2020).

[8] Ibidem.

[9] Ibidem.

[10] The birth rate in Croatia in 2016 was –3.4. Državni zavod za statistiku [State Statistical Bureau Croatia], *Prirodno kretanje stanovništva Republike Hrvatske u 2016* [Natural change of population of the Republic of Croatia]. Available at: https://www.dzs.hr/Hrv_Eng/publication/2017/07-01-01_01_2017.htm (accessed 27.10.2020).

[11] Eurostat, *Population structure and ageing*. Available at: http://ec.europa.eu/eurostat/statistics-explained/index.php/Population_structure_and_ageing#Further_Eurostat_information (accessed 27.10.2020).

[12] Državni zavod za statistiku, *Census 2011*. Available at: https://www.dzs.hr/hrv/censuses/census2011/results/htm/H01_01_18/H01_01_18.html (accessed 27.10.2020).

[13] Eurostat, *Population structure*, op. cit.

10.1% will be people aged 80 and over.[14] In the EU Member States, the largest share of older people in 2019 was recorded in Italy (22.8%), followed by Greece (22.0%), Portugal and Finland (21.8% each), Germany (21.5%) and Bulgaria (21.3%). Ireland (14.1%) and Luxembourg (14.4%) have the lowest shares of the elderly. In 2019, 20.3% of the EU population was older than 65, which is 0.3 percentage points more than the year before, and 2.9 percentage points more than a decade earlier. With a 20.5% share of people over 65 in the total population, which is about 838,000 citizens, Croatia is slightly above average.[15]

Aging is primarily a biological process which brings a higher frequency of health problems, both physical and mental. However, it would be incorrect to equate older age, which in itself is difficult to define, with the period when (statistically) a major health impairment begins.[16] This is clearly emphasised by the World Health Organisation (WHO) when it states that it is important to distinguish chronological age and the functional capacity of each individual.[17] However, there is no doubt that certain diseases, e.g. mental disorders, occur more frequently among the elderly,[18] which makes the elderly twice as vulnerable, i.e. vulnerable on two grounds – due to age and health condition. The latter should be of cardinal importance when talking about the need of enhanced legal protection of the elderly. In addition, psychological and social aspects of aging must be taken into account, and that requires countries to take positive action – implement social programmes to improve the quality of life of the elderly. Increased

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[14] United Nations, *World Population Prospects: The 2015 Revision*, p. 27. Available at: https://esa.un.org/unpd/wpp/publications/files/key_findings_wpp_2015.pdf (accessed 27. 10.2020). In this document, persons aged 60 or over as regarded as elderly persons.

[15] This raised concerns in the Croatian media, particularly concerning the COVID-19 pandemic. Cf. Ljubica Gatarić, "Hrvatska ima 385 tisuća starijih od 75 godina, po udjelu starijih od 65 smo lagano iznad EU prosjeka". Available at: https://www.vecernji.hr/vijesti/hrvatska-ima-385-tisuca-starijih-od-75-godina-po-udjelu-starijih-od-65-smo-lagano-iznad-eu-prosjeka-1391416 (accessed 28.10.2020).

[16] Spomenka Tomek-Roksandić, Nada Tomasović Mrčela, Zvonimir Šostar, Nina Smolej Narančić, Mate Ljubičić, Manuela Maltarić, Marica Lukić, Dunja Durut-Beslač, Višnja Fortuna, Stela Mravak, Ivana Popek, Alexandra Julia Lechner, *Zaštita zdravlja starijih osoba u hrvatskoj – gerontološkojavnozdravstveni menadžment*. In: Iva Sorta-Bilajac Turina, Helena Glibotić Kresina, Svjetlana Gašparović Babić, Nevenka Vlah, Suzana Janković (eds.), *Zdravstveni prioriteti u brizi za osobe starije životne dobi – pregled radova i sažetaka*. Opatija 2015, pp. 15–26. Available at: http://www.stampar.hr/sites/default/files/Aktualno/Dogadjanja/pregled_radova_i_sazetaka.pdf (accessed 27.10.2020).

[17] World Health Organisation, *World Report on Ageing and Health 2015*, pp. 7–8. Available at: http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf (accessed 27.10.2020).

[18] World Health Organisation, *The World Health Report 2001 – Mental Health: New Understanding, New hope*, p. 43. Available at: http://www.who.int/whr/2001/en/whr01_en.pdf?ua=1 (accessed 27.10.2020).

needs of the older population and specific long-term (health) care, especially in the elderly with mental or physical disabilities.[19] The market has already begun reacting to the stated facts.[20]

Thus, the aging process of the population requires an appropriate legal response on regional and global level, which has not as yet been adopted or has been adopted but has not been widely accepted, as we will show in the third chapter of this article. It is indisputable that the protection of the health of the elderly is one of the main indicators of progress or omissions in protecting the health of the entire population. Namely, age is a normal physiological phenomenon, and aging with technological development is considered the greatest achievement of the 21st century. As Tomek-Roksandić and co-workers stated:

> [...] fortunately, we are witnessing evolutionary changes, we are not accepting any more wrong attitudes, prejudices and stereotypes in the perception of the elderly and old age, especially in the developed countries. Today, the image of passive age is untrue, and this perception receives the sharpest condemnation and shows the ignorance of what old age and aging are.[21]

With this article, we point out the illogicallity that prevail in the field of internationally recognised human rights. The paper is based on the claim that all vulnerable groups, such as the elderly, children and people with disabilities, demand increased protection of their rights and interests from society, while respecting additional differences within these groups which are based on other characteristics, e.g. gender.[22] To accomplish the aim of this article, which is to analyse whether there is a need, from the perspective of the Republic of Croatia, to support the drafting and adoption of the Convention for the Protection of the Rights of the Elderly under the auspices of the United Nations, we will briefly present the current state of regulations on special rights of the elderly at international, European and national level. At the same time, we will look at relevant judgments of the European Court of Human Rights when we expose the main problems that older people face, especially those with mental disorders,

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[19] The European Union predicts that the share of public expenditure on long-term care (LTC) will increase from 1.8% of GDP in 2010 to 3.4% of GDP in 2060. European Commission, *The 2012 Ageing Report*. Available at: http://ec.europa.eu/economy_finance/publications/european_economy/2012/pdf/ee-2012-2_en.pdf (accessed 27.10.2020).

[20] Danielle Muoio, "Japan is running out of people to take care of the elderly, so it's making robots instead". *Business Insider* (20.11.2015). Available at: http://www.businessinsider.com/japan-developing-carebots-for-elderly-care-2015-11 (accessed 27.10.2020).

[21] Tomek-Roksandić et al., *Zaštita zdravljaet*..., op. cit., p. 15.

[22] World Health Organisation, *Multisectoral action for a life course approach to healthy ageing: draft global strategy and plan of action on ageing and health*, p. 8. Available at: https://apps.who.int/iris/handle/10665/252671 (accessed 27.10.2020).

in the Republic of Croatia. Based on an analysis of the existing rights, we will suggest what rights this Convention could and should contain.

The topic of the paper was selected and written following Lasswell and McDougal's approach[23] – the subject of research cannot be analysed outside the social context: rules have semantic content, and therefore their meaning largely depends on the interpreter, who interprets them in a way predetermined by social, historical and cultural conditions. Therefore, as we did in the introductory part of this article, the researcher needs to identify the values and points of view from which the topic is discussed, and expose one's own hierarchy of values. This approach, in our view, is necessary when dealing with topics with value content as it is the subject of this paper. The fact that international law rests on a tradition of legal realism of accepting explicit and desirable application of law to achieve social goals, cannot be ignored. This is especially important when the law is analysed within social context.

2. The concept of the elderly

Unlike the term "children", which is most often defined to include persons under the age of 18, the notion of an elderly person is nowhere near a generally accepted definition. While the development of children can be generalised in terms of physical and also mental development according to their age in, the same is impossible to do in determining when an individual begins to age. Namely, the average living age is only a generalisation. The "old age" is marked by a wide disparity of different physical and psychological conditions. It is enough for us to look at, for example, life expectancy age in Sierra Leone, which is 50.1 years, while in Croatia it is 78 years.[24]

At the state and regional level, however, defining old age is easier. Although generally not defined *explicite*, the term "old age" is associated with the prescribed age of retirement, which in the developed world is most commonly between 60 and 67 years of age. It is also about the age when certain social privileges of aged groups can be used. But that is exactly where one of the main misconceptions lies. Many elderly people are still functional, that is, their functional ability is preserved and, especially nowadays, retirement age should not be equated with the term "elderly", whether it is considering developed or developing countries. However, with the ultimate goal of enacting the Convention on the Rights of the Elderly,

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[23] Harold D. Lasswell, Myres S. McDougal, "Legal education and public policy: Professional training in the public interest". *Yale Law Journal* 52 (1943), pp. 203–295.

[24] World Health Organisation, *World Health Statistics 2016: Monitoring health for the SDGs*, p. 8. Available at: http://www.who.int/gho/publications/world_health_statistics/2016/en/ (accessed 27.10.2020).

determining the chronological age from which the older age "begins" is set as a *conditio sine qua non* for the possibility of applying the rights and obligations of such a Convention in particular, and because, in our view, such a convention should include positive discrimination with regard to the elderly. It is still worth emphasising that both old age and disease are not synonymous, and this is where, in our opinion, a special Convention would help to move the rights of the elderly away from the expected rights related mainly and/or only to health and social protection. Although the definition of old age is changing, aging is a natural, normal physiological phenomenon, an irreversible individual process, which in individual people progresses at different speeds at different ages.

The United Nations usually defines the age of 60 as old age. General Comment No. 6 of the Commission of the International Economic, Social and Cultural Rights Committee[25] states that older people are those who have reached the age of 60 years and above; however, there is no generally accepted definition. Older age, how it is often pointed out in the Republic of Croatia, is divided by the World Health Organisation into early (from 65 to 74), middle (from 75 to 84) and deep old age (from 85 and over).[26] Other statistical reports of the World Health Organisation consider the age of 60 as the beginning of old age, depending on the region.[27] According to Eurostat, it is set at 65 years.[28]

All of the above are definitions which use chronological age for determining when the beginning of old age starts. However, as already mentioned in the Introduction, life expectancy is neither fixed nor constant, but tends to constantly

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[25] CESCR General Comment No. 6: The Economic, Social and Cultural Rights of Older Persons. United Nations Committee on Economic, Social and Cultural Rights (8.12.1995). Available at: https://www.refworld.org/pdfid/4538838f11.pdf (accessed 27.10.2020); Diego Rodrigez-Pinzon, Claudia Martin, "The International Human Rights Status of Elderly Persons". *The American University International Law Review* 18 (2003), pp. 915–1008.

[26] Grad Zagreb, *Vodič za starije građane grada Zagreba* [Guide for senior citizens of the City of Zagreb]. Zagreb 2013. Available at: http://www1.zagreb.hr/vodics/Vodic_za_starije_gradjane_2013.pdf (accessed 27.10.2020).

[27] Tomek-Roksandić et al., *Zaštita zdravlja...*, op. cit. Also cf. "Over 20% of adults aged 60 and over suffer from a mental or neurological disorder (excluding headache disorders) and 6.6% of all disability (disability adjusted life years-DALYs) among over 60s is attributed to neurological and mental disorders. These disorders in the elderly population account for 17.4% of Years Lived with Disability (YLDs). The most common neuropsychiatric disorders in this age group are dementia and depression. Anxiety disorders affect 3.8% of the elderly population, substance use problems affect almost 1% and around a quarter of deaths from self-harm are among those aged 60 or above". World Health Organisation, *Mental health for older adults*. Available at: http://www.who.int/mediacentre/factsheets/fs381/en/ (accessed 30.10.2017).

[28] Cf. e.g. Eurostat, *People in the EU – statistics on an ageing society*. June 2015. Available at: http://ec.europa.eu/eurostat/statistics-explained/index.php/People_in_the_EU_%E2%80%93_statistics_on_an_ageing_society (accessed 27.10.2020).

increase. Therefore, when observing the old age as a relative term largely dependent on life expectancy, the most ideal definition of old age would be one that will be both fluid and adaptable in the spatial and temporal dimension, linking the formal legal appearance of older age (and thus the possibility of exercising the rights that are vested in the elderly) with the average lifespan of a particular area. Thus, for example, starting from 2022, the retirement age in the Netherlands will be linked to the average life expectancy.[29]

3. Protection of the rights of the elderly in international law

3.1. Accession to the drafting of the United Nations Convention

If we start from the initiatives, the first initiative for the existence of a single global approach to the protection of the elderly person was launched in 1948 by Argentina, in the form of a Draft Resolution on the Declaration on the Rights of the Elderly.[30] In its ten articles, the Draft took into account the need for accommodation, food, clothing, physical and mental health, rest, work and financial stability of the elderly, and emphasised the right to assistance from the family and the state as well as the right of respect for such persons.[31] It also discussed the special recognition of the rights of the elderly in the drafting of the International Covenant on Economic, Social and Cultural Rights adopted in 1966.[32] An explicit reference to the elderly within the International Covenant was rejected for the reason that "the rights of the elderly could be ensured through a special convention".[33] The initiative for special protection of the rights of the elderly was launched in 1969 by Malta, which requested the UN General Assembly to consider the "Issues of the older people and the elderly" in 1973.[34]

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[29] Cf. Sociale Verzekeringsbank, *Insurance under the AOW scheme*. Available at: https://www.svb.nl/en/aow-pension/aow-pension-age/your-aow-pension-age (accesses 15.09.2021).

[30] Paul De Hert, Eugenio Mantovani:, "Specific human rights for older persons?". *European Human Rights Law Review* 4 (2011), p. 400.

[31] Ibidem.

[32] International Covenant on Economic, Social and Cultural Rights. United Nations General Assembly. Available at: https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx (accessed 27.10.2020).

[33] De Hert, Mantovani, "Specific...", op. cit., citing Matthew C.R. Craven, *The International Covenant on Economic, Social and Cultural Rights: A Perspective on its Development*. Oxford 1995, p. 25, footnote 149.

[34] Question of the elderly and the aged. United Nations General Assembly Resolution 3137 (14.12.1973). Available at: https://undocs.org/en/A/RES/3137(XXVIII)&Lang=E&Area=RESOLUTION (accessed 27.10.2020); Arlene S. Kanter, "The United Nations Convention on the Rights of Persons with Disabilities and its Implication for the rights of elderly people under international law". *Georgia State University Law Review* 25 (2009), p. 534.

Later, in 1982, the UN General Assembly adopted the International Action Plan on Aging in Vienna,[35] which called for steps to be taken in the field of health and nutrition, protection of elderly consumers, accommodation and the environment, families, social welfare, income security, education, data collection and data processing. In December 1991, the General Assembly also adopted the UN Principles on the Elderly[36] listing 18 principles that Member States are encouraged to incorporate into their own legislation.

Despite the effort by several countries, a special Convention for the Protection of the Rights of the Elderly has not been enacted as yet. Recently, however, there have been positive shifts on the level of the United Nations towards the actual start of the work on the drafting and adoption of the Convention. The adoption of the Political Declaration and the Madrid Action Plan on Aging ("Madrid Action Plan"), adopted in April 2002,[37] has helped here, so as the establishment of the *Open-ended Working Group in Aging* with the UN General Assembly Resolution 65/182[38] from December 2010, together with the appointment of an independent expert on the enjoyment of all human rights by the elderly (2014).[39] The Madrid Action Plan aimed to give guidance to policy makers on how to adapt social arrangements to the aging population. The plan focused on three areas: the elderly and their development, promoting health and wellbeing in old age, and providing a stimulating and supportive environment.

The UN Working Group on Aging was set up to strengthen the protection of human rights of the elderly by analysing the existing system of international human rights and by identifying possible shortcomings and finding ways to address them, including considering the adoption of new instruments and measures (i.e. new conventions).[40] After analysing the results of the Working Group,

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[35] United Nations, *Report of the World Assembly on Aging.* New York 1982. Available at: https://www.un.org/esa/socdev/ageing/documents/Resources/VIPEE-English.pdf (accessed 27.10.2020).

[36] United Nations Principles for Older Persons. United Nations General Assembly Resolution A/RES/46/91. Available at: https://undocs.org/A/RES/46/91 (accessed 27.10.2020).

[37] Political Declaration and Madrid International Plan of Action on Ageing. United Nations. Available at: http://www.un.org/esa/socdev/documents/ageing/MIPAA/political-declaration-en.pdf (accessed 27.10.2020).

[38] Resolution adopted by the General Assembly on 21 December 2010: Follow-up to the Second World Assembly on Ageing. United Nations General Assembly. Available at: https://undocs.org/en/A/RES/65/182 (accessed 27.10.2020).

[39] Thematic study on the realisation of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. United Nations General Assembly, A/HRC/18/37. Available at: http://hrbaportal.org/wp-content/files/A-HRC-18-37_en.pdf (accessed 27.10.2020).

[40] Political Declaration..., op. cit., p. 28.

in its Resolution 67/139[41] from December 2012, the United Nations General Assembly reaffirmed the need for a new Convention, which we consider a big step forward. In it, the Working Group on Aging is instructed to begin considering proposals for an international legal instrument that would promote and protect the rights and dignity of the elderly using a holistic approach including social development, human rights, non-discrimination, gender equality and women's empowerment.[42] Also, the Working Group on aging is required to present to the General Assembly, as soon as possible, a proposal which would contain, *inter alia*, the main elements that should be included in an international legal instrument which would promote and protect the rights and dignity of the elderly persons, whose protection is currently not sufficiently secured by the existing legal instruments.[43] In the further analysis of this paper, we will therefore look at the existing solutions on regional level to give our own proposal on the rights that the Convention must include.

Before moving on to regional solutions, we must underline that a special UN Convention on the Rights of the Elderly must in any case follow the approach applied by the UN Convention on the Rights of Persons with Disabilities. As stressed by Kanter:

> the Convention on the Rights of Persons with Disabilities represents a turnaround from using a medical approach to people with disabilities to an approach based on respect for their human rights. This turn is perhaps most noticeable in Art. 1 of the Convention, which emphasises that the purpose of the Convention is to promote, protect and secure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promoting respect for their innate dignity.[44]

It was this Convention that served as one of the main role models for the development of a new Croatian Law on the Protection of Persons with Mental Disabilities, which elaborates in detail the rights of persons with mental disorders and approaches them from a human rights perspective, following the shift (paradigm shift) done in the Convention on the Rights of Persons with Disabilities.[45]

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[41] Resolution adopted by the General Assembly on 20 December 2012: Towards a comprehensive and integral international legal instrument to promote and protect the rights and dignity of older persons. United Nations General Assembly. Available at: https://undocs.org/en/A/RES/67/139 (accessed 27.10.2020).

[42] Ibidem.

[43] Ibidem.

[44] Kanter, "The United Nations...", op. cit., p. 549. Cf. footnote 102 for the interpretation of this provision.

[45] The Final Proposal of the Law on the Protection of People with Mental Disabilities [Konačni prijedlog Zakona o zaštiti osoba s duševnim smetnjama]. Ministry of Justice, p. 31.

Although no special attention is paid to the elderly in the Law on the Protection of Persons with Mental Disabilities, provisions prescribing a ban on research on persons who cannot themselves agree to it, directly protect the right of autonomy of the elderly and protect them against potential abuse.[46]

3.2. Positive examples at regional level outside Europe

At the regional level, significant progress has been made in North and South America by the adoption of the Inter-American Convention for the Protection of the Human Rights of the Elderly (hereinafter: Inter-American Convention) on 15 June 2015, which entered into force on 11 January 2017.[47] It specifically regulates the protection of the human rights of the elderly, explicitly recognising their right to equality and non-discrimination on grounds of age (Article 5), the right to life and dignity in older age (Article 6), the right to independence and autonomy (Article 7), the right to participate and integrate into social life (Article 8), the right to security and a life free from any form of violence (Article 9), the right not to be subjected to torture or any other cruel, inhuman or degrading treatment procedure (Article 10). The definition of an elderly person is given in Article 2 and applies to an elderly person aged 60 or over, unless the legislation (of the States Parties) prescribes another age, provided it is not above 65 years.[48]

Article 11 regulates in particular the right to free and informed consent in health matters. Furthermore, it regulates the right to receive long-term care (Article 12), the right to personal liberty (Article 13), the right to liberty of thought and expression and access to information (Article 14), the right to citizenship and freedom of movements (Article 15), the right to privacy and intimacy (Article 16), the right to social welfare (Article 17) and, very importantly, primarily because of the perception of the elderly with “retirement”, the right to work (Article 18). Article 19 additionally regulates in detail the right to health, specifically

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Available at: http://www.sabor.hr/konacni-prijedlog-zakona-o-zastiti-osoba-s-dusevni (accessed 27.10.2020).

[46] In this regard, although aware of its setbacks, the authors welcome such a legal solution at this moment, as long as the transparency of research concerning such persons is not fully guaranteed. Velinka Grozdanić (ed.), *Komentar Zakona o zaštiti osoba s duševnim smetnjama*. Rijeka 2015, pp. 85–90.

[47] Inter-American Convention on Protecting Human Rights of Older Persons. Organisation of American States. Available at: http://www.oas.org/en/sla/dil/inter_american_treaties_a-70_human_rights_older_persons.asp (accessed 27.10.2020).

[48] “[...] Older person: A person aged 60 or older, except where legislation has determined a minimum age that is lower or higher, provided that it is not over 65 years. This concept includes, among others, elderly persons [...]”. Ibidem, Article 2.

mentioning, *inter alia,* promotion of public policies on sexual and reproductive health of the elderly and promotion of public policies to improve the nutrition of the elderly. Attention is also given to mental disorders that more often affect the elderly, and it is letter (h) of the said article which prescribes support for the development of specialised social and health services for the elderly to treat diseases that lead to addiction to others, including chronic degenerative diseases, dementia and Alzheimer's disease. In the Inter-American Convention, several articles (Articles 6, 12 and 19) also establish the need for palliative care, prescribing the encouragement of measures to ensure that palliative care services are available to all older people, so as support for their families. Furthermore, the Inter-American Convention prescribes the right of the elderly to education (Article 20), participation in cultural life (Article 21), recreation, leisure and sport (Article 22), the right to property (Article 23), the right to accommodation (Article 24), the right to a healthy environment (Article 25), the right to easy access (*accessibility*) and personal mobility (Article 26), political rights (Article 27), the right of assembly and association (Article 28), insurance in case of risks and humanitarian disasters (Article 29) and, finally, the equality of all before the law (Article 30) and the right of access to courts (Article 31). The Inter-American Convention for the Protection of Human Rights of the Elderly is in force in Argentina, Bolivia, Chile, Costa Rica and Uruguay.[49] We believe, therefore, that the notion of age discrimination, *ageism*, will grow into a widely accepted term that will also draw attention to the rights of the elderly, and not only serve as a basis for determining responsibility, but as defined in the Inter-American Convention in Article 2:

> any distinction, exclusion or limitation based on age, with the aim or consequence of denying or restricting recognition or enjoyment, on the principle of equality, of human rights and fundamental freedoms in political, cultural, economic, social life, or any other sphere of public and private life.

Significant progress in the field of rights of the elderly is also being made by the African Union, which adopted the Draft in 2014, and in 2016 the Protocol to the African Charter on Human Rights and the Rights of the People on the rights of the elderly in Africa[50] (hereinafter: Protocol) which is yet awaiting

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[49] Inter-American Convention on Protecting Human Rights of Older Persons. Signatories and Ratifications. Organisation of American States. Available at: http://www.oas.org/en/sla/dil/inter_american_treaties_A-70_human_rights_older_persons_signatories.asp (accessed 27.10.2020).

[50] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa. African Union. Available at: https://au.int/sites/default/files/pages/32900-file-protocol_on_the_rights_of_older_persons_e.pdf (accessed 27.10.2020).

entry into force. The Protocol is based on Article 18, paragraph 4, of the African Charter on Human Rights and the Rights of the People[51] (hereinafter: The African Charter) according to which elderly persons and persons with disabilities are entitled to special protection measures in accordance with their physical and moral needs. The Protocol further refers to Article 2 of the African Charter which stipulates that every individual has the right to enjoy rights and freedoms enshrined in the Convention regardless of race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, wealth, birth, or some other characteristic.[52] Thus the Protocol actually follows what is often repeated in the admittedly insufficiently numerous scientific articles which advocate the need for special regulation to protect the rights of the elderly: the protection of human rights and dignity should be the basis of a special regulation.[53] Violation of every human right is a violation of human dignity, and that is most visible precisely in ways of abusing the elderly.[54]

The Protocol prohibits all forms of discrimination against the elderly, encourages the elimination of social and cultural stereotypes which marginalise the elderly (Article 3), and prescribes equal protection before the law and access to justice (Article4). Workplace discrimination is prohibited by Article 6, and, as in the Inter-American Convention, the right of older persons to make decisions is mentioned. Article 7 also prescribes universal social protection (pension). Additional prescribed rights are similar to those prescribed in the Inter-American Convention, however they are much more elaborated in the latter. The Protocol also has certain peculiarities relating to the African Cultural Circle, therefore prescribing protection of older women (Article 9), as well as protection from abuse and harmful traditional practices (Article 8). Special provisions are made on supporting older persons who are taking care of vulnerable children

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[51] Ibidem.

[52] In addition, the Protocol refers to a number of international documents, such as the Convention on the Elimination of Racial Discrimination (CERD) of 1965; International Covenant on Civil and Political Rights (ICCPR) of 1966; International Covenant on Economic, Social and Cultural Rights (ICESCR) of 1966; The Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) of 1979; United Nations Plan of Action on Ageing of 1982; The Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) of 1984; UN Declaration on the Right to Development of 1986; United Nations Principles for Older Persons of 1991; United Nations Proclamation on Ageing of 1992; Madrid Plan of Action on Ageing (MIPAA) of 2002.

[53] Barbara Mikołajczyk, "Is the ECHR ready for global ageing?". *The International Journal of Human Rights* 17 (2013), p. 514.

[54] Silvia Rusac, "Zlostavljanje i zanemarivanje starijih osoba u obitelji". In: Spomenka Tomek-Roksandić, Zvonimir Šostar, Višnja Fortuna (eds.), *Četiri stupnja gerijatrijske zdravstvene njege sa sestrinskom dokumentacijom i postupnikom opće/obiteljske medicine u domu za starije osobe*. Zagreb 2012.

(Article 12), on the importance of adopting measures that would raise awareness among younger population on aging and help educate them. In that vein, it is necessary to develop training programmes that prepare individuals for the challenges faced in the old age (Article 19). The Protocol does not stop only at prescribing the rights of the elderly. In its Article 20, it also defines the duties of the elderly towards their families, communities, the wider society, the state and the international community. In this regard, they have the responsibilities of mentoring and passing on knowledge and experience to the younger generation, fostering and facilitating inter-generational dialogue and solidarity within their families and communities, and playing a role in mediation and conflict resolution. The Protocol, like the Inter-American Convention, defines an older person as a person aged 60 or above. However, it does not leave the possibility of a different definition to individual countries. Thereby, the Protocol does not take into account the average life expectancy, which, as already quoted, in Sierra Leone, a member state of the African Union, is 50 years.[55] The Protocol has not yet entered in force – it has been signed by four of the 55 African Union countries.[56] This is still valid in 2020. The entry into force is still awaited.[57]

3.3. Rights of older persons in Europe

3.3.1. Council of Europe

The Council of Europe's most important documents for the rights of older persons (and human rights in general) include the European Convention for the Protection of Human Rights and Fundamental Freedoms[58] (hereinafter: ECHR, Convention), together with its protocols, and the European Social Charter of 1961, revised in 1996.[59] Important provisions considering the right to health and the personal healthcare decision-making autonomy remain within the scope

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[55] Lasswell, McDougal, *Legal education...*, op. cit.

[56] *OAU/AU Treaties, Conventions, Protocols & Charters*. African Union. Available at: https://au.int/en/treaties/protocol-african-charter-human-and-peoples%E2%80%99-rights-rights-older-persons (accessed 30.11.2017).

[57] *List of countries which have signed, ratified/acceded to the Protocol to the African charter on human and peoples' rights on the rights of older persons*. African Union. Available at: https://au.int/sites/default/files/treaties/36438-sl-PROTOCOL%20TO%20THE%20AFRICAN%20CHARTER%20ON%20HUMAN%20AND%20PEOPLES%E2%80%99%20RIGHTS%20ON%20THE%20RIGHTS%20OF%20OLDER%20PERSONS.pdf (accessed 27.10.2020).

[58] European Convention on Human Rights. European Court of Human Rights–Council of Europe. Available at: https://www.echr.coe.int/documents/convention_eng.pdf (accessed 27.10.2020).

[59] European Social Charter. Council of Europe, Treaty No. 163. Available at: https://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168006b642 (accessed 27.10.2020).

of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine with additional protocols[60] which, however, does not explicitly mention the elderly.

The ECHR does not explicitly mention older persons in any of its parts, but all the rights prescribed by the Convention also apply to the elderly. For this reason, an analysis of the law of the Convention is not possible without analysing the jurisprudence of the ECHR. The rights of older persons were discussed, *inter alia*, in the context of Article 2 of the Convention on the Right to Life, Article 3 on the prohibition of torture and inhuman or degrading treatment or punishment, Article 4 on the prohibition of slavery and forced labour, Article 5 on the right to liberty and security, Article 6 on the right to a fair trial, Article 8 on the right to respect for family and private life, Article 10 on freedom of expression, Article 12 on the right to marry, Article 14 on prohibition of discrimination and Article 1 of Protocol No. 1. to the Convention, on the protection of private property.[61] In the next chapter (4), in which we analyse the most common violations concerning older persons that occur in the Republic of Croatia, we refer to some of the above judgments.

It can be expected, as Mikołajczyk points out, that the Convention and the ECHR jurisprudence does not cover all the rights that should be guaranteed to older persons, such as numerous cultural rights and participation in cultural life, together with insufficient protection of other economic and social rights of older persons. Because of that, Mikołajczyk further suggests:

> It may be worth considering, at the European forum, the adoption of a compromise solution of developing and adopting a supplementary protocol to the ECHR regarding the protection of the rights of older persons. So far, no protocol dedicated to a vulnerable group has been adopted. However, considering the challenges for human rights posed by demographic change, it would be advisable to take this question into account and to 'prepare' the ECHR for the imminent change. This is not about creating new human rights for older persons, but about linking older persons to the human rights included in the effective treaties, specifically the ECHR. [...] The protocol should contain primarily a catalogue of positive obligations of states in the scope of eliminating barriers to older persons exercising their human rights.[62]

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[60] The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. Council of Europe, Treaty No. 164. Available at: https://www.coe.int/en/web/bioethics/oviedo-convention (accessed 27.10.2020).

[61] *Elderly people and the European Convention on Human Rights*. European Court of Human Rights Factsheet (2016). Available at: http://www.echr.coe.int/Documents/FS_Elderly_ENG.pdf (accessed 27.10.2020).

[62] Mikołajczyk, "Is the ECHR...", op. cit., pp. 523–524.

The European Social Charter (revised in 1996), unlike the Convention, explicitly mentions the elderly in Article 23, entitled "The right of the elderly persons to social protection". It provides that,

> with a view to ensuring the effective exercise of the right of elderly persons to social protection, the Parties shall undertake to adopt or encourage, either directly or in cooperation with public or private organisations, appropriate measures designed in particular to enable the elderly persons to remain full members of society for as long as possible, by means of adequate resources enabling them to lead a decent life and play an active part in public, social and cultural life as well as with provision of information about services and facilities available for elderly persons and their opportunities to make use of them.

Furthermore, the Parties commit "to enable elderly persons to choose their lifestyle freely and to lead independent lives in their familiar surroundings for as long as they wish and are able, by means of provision of housing suited to their needs and their state of health or of adequate support for adapting their housing and healthcare as well as with the services necessitated by their state". Finally, it is necessary to "guarantee appropriate support to elderly persons living in institutions, while respecting their privacy, and participation in decisions concerning living conditions in the institution."

Among the legally non-binding documents of the Council of Europe are the Parliamentary Assembly resolutions and recommendations, recommendations of the Committee of Ministers as well as the activities of the Commissioner for Human Rights.[63] The most significant[64] is the Recommendation on the promotion of human rights of older persons, adopted by the Committee of Ministers on 19 February 2014.[65]

It is to expect that after the end of the COVID-19 pandemic, where the elderly are the most vulnerable victims, special emphasis will be given to the protection of their rights alongside preservation of their health.

3.3.2. European Union

Protection of human rights in the European Union, and therefore the rights of the elderly, is based on the Charter of Fundamental Rights of the European

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[63] Rešetar Čulo, "Zaštita prava...", op. cit., p. 127.

[64] For other recommendations and resolutions of the Parliamentary Assembly, which *inter alia* apply to the elderly, cf. ibidem, footnote 91.

[65] Recommendation of the Committee of Ministers to Member States on the promotion of human rights of older persons. Council of Europe, CM/Rec(2014)2. Available at: https://search.coe.int/cm/Pages/result_details.aspx?ObjectID=09000016805c649f (accessed 27.10.2020).

Union[66] (Charter). Article 25, entitled "Rights of the elderly", stipulates that "The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life". This provision is based on Article 23 of the revised European Social Charter (q.v.) and Articles 24 and 25 of the (European) Charter of the Fundamental Social Rights of Workers (1989).[67] Participation in social and cultural life also includes participation in political life.[68]

Immediately after the recognition of the rights of the elderly, in its Article 26 entitled "Integration of persons with disabilities", the Charter recognises and respects the right of persons with disabilities[69] to "benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community". This article is based on Article 15 of the European Social Charter and Article 26 of the (European) Charter of the Fundamental Social Rights of Workers.[70]

Finally, Article 21 of the Charter prohibits discrimination on a wide range of grounds, including age and disability. Implementation of these legal instruments is primarily in the responsibility of the national courts of the EU Member States.

In conclusion, it is to be hoped that the climate among some EU Member States will soon change regarding the support for the drafting of the Convention. As Van Bueren[71] stated, "a number of European countries, as well as the United States of America and Australia, have opposed the need for a specific treaty, arguing that the obstacle to better protecting the rights of older persons is not an absence of law but a question of better implementation."[72] Van Bueren points out that the same arguments were used in the drafting of the Convention on the Rights of the Child.[73] As arguments behind such an attitude, she indicates the fear of new costs, which she considers unjustified, citing the fact that older

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[66] Charter of Fundamental Rights of the European Union. *Official Journal of the Europan Union* C 326. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=OJ:C:2012:326:FULL&from=EN (accessed 27.10.2020).

[67] Explanations relating to the Charter of Fundamental Rights. *Official Journal of the European Union*, C 303/17. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=OJ:C:2007:303:FULL&from=EN (accessed 27.10.2020).

[68] Ibidem.

[69] Including persons with mental disabilities.

[70] Ibidem.

[71] Geraldine Van Bueren, *The case for a convention on the rights of older people*. Available at: https://www.ageinternational.org.uk/policy-and-research/human-rights/Geraldine-Van-Bueren-QC/ (accessed 27.10.2020).

[72] Ibidem.

[73] Ibidem.

workers created "a net benefit of USD 40 billion through the payment of tax, as consumers and through unpaid care."[74]

4. Protection of older persons in the Republic of Croatia

The basis of human rights in the Republic of Croatia is the Constitution of the Republic of Croatia.[75] The provisions of Articles 58, 64 and 65 of the Constitution are of great importance for the elderly and persons with mental disabilities. Article 58, paragraph 1 prescribes the duty of the state to ensure the right to assistance for weak, infirm or other persons unable to meet their basic subsistence needs as a result of their unemployment or incapacity for work. Its paragraph 2 obliges the state to devote special care to the protection of persons with disabilities and their inclusion in social life. Article 65, paragraph 1 prescribes the duty of all to protect children and infirm persons while Article 64, paragraph 4 prescribes the obligation of children to care for their elderly and infirm parents, also elaborated in Article 292 of the Family Act.[76] The status of the elderly and persons with mental disorders in the social welfare system is defined by the Social Welfare Act,[77] which recognises them as a category of beneficiaries if they are unable to ensure their own essentials for living.[78] The social welfare system establishes, among other things, certain important rights for the elderly – allowances (guaranteed minimum allowance, housing and heating allowance, personal allowance for an accommodation beneficiary, one-off allowance, assistance and care supplement, personal disability allowance) as well as the right to social services of accommodation and home assistance.[79] The Foster Care Act as a basis for emergency foster care[80] (for a maximum uninterrupted period of one

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[74] Ibidem.

[75] Constitution of the Republic of Croatia [Ustav Republike Hrvatske]. *Official Gazette of the Republic of Croatia "Narodne novine"*, Nos. 56/90, 135/97, 8/98, 113/00, 124/00, 28/01, 41/01, 55/01, 76/10, 85/10, and 5/14.

[76] Family Law [Obiteljski zakon]. *Official Gazette of the Republic of Croatia "Narodne novine"*, No. 103/15.

[77] Social Welfare Act [Zakon o socijalnoj skrbi], *Official Gazette of the Republic of Croatia "Narodne novine",* No. 157/13, 152/14, 99/15, 52/16, 16/17.

[78] Ibidem, Article 21.

[79] Social Welfare Strategy for the Elderly in the Republic of Croatia for the period from 2017 to 2020 [Strategija socijalne skrbi za starije osobe u Republici Hrvatskoj za razdoblje od 2017–2020]. Ministry of Demography, Family, Youth and Social Policy of the Republic of Croatia, Zagreb 2017, p. 11. Available at: http://www.mspm.hr/UserDocsImages/Vijesti2017/Strategija%20socijalne%20skrbi%20za%20starije%20osobe%20u%20RH%20za%20razdoblje%20od%202017.-2020.%20g.pdf (accessed 30.11.2017).

[80] "Emergency foster care is foster care which, for the sake of his safety, protection or other vital interests, must urgently provide him with temporary accommodation in a foster family

month),[81] among other things, prescribes a situation when an adult needs urgent care because: he/she is elderly, infirm, abandoned, dependent on the assistance and care of another person, or left without a home due to a natural disaster, or a victim of violence, or after the death of a parent who cared for a person with a disability and there is no one to continue to take care, or if the adult's vital interest is endangered.[82] In terms of health protection, it is worth mentioning that since 2013, the Reference Centre for the Protection of the Health of the Elderly has been operating within the Ministry of Health of the Republic of Croatia.[83]

Positive development in the field of recognising the problem of population aging and the rights of the elderly has been made by the current Social Welfare Strategy for Older People in the Republic of Croatia for the period 2017–2020,[84] adopted in September 2017. The Strategy identifies the following problems: unequal conditions of access to the network of social services for users and providers, i.e. uneven models of financing homes for the elderly, insufficient supervision of the work of service providers for the elderly, insufficient socio-economic protection of the elderly (national pension) and inability to exercise the right to status of caregivers for the care of the elderly.[85] Furthermore, the problem of insufficient knowledge on the rights of the elderly was identified. It is planned to be tackled by measures monitoring violations of the rights of the elderly (together with recommendations based on the monitoring results), and measures to create preconditions for informing and raising awareness of the rights of the elderly carried out in cooperation with civil society organisations.[86] The problem of insufficient and uneven availability of services for the elderly in the entire territory of the Republic of Croatia is also recognised and is sought to be solved with the plan of increasing the availability of services for the elderly by equalising the availability of accommodation for the elderly and developing services for the elderly to stay in their homes (in collaboration with local government units).[87] In cooperation with civil society organisations, the plan is to provide services aimed at increasing the quality of life of the elderly by organising daily activities and encouraging older persons to volunteer.[88] Also, the intention is to increase

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until the end of that situation and the creation of conditions for his return to his own family or other forms of care in accordance with with his individual plan of change". Ibidem, Article 11, paragraph 1.

[81] Ibidem, paragraph 4.

[82] Ibidem, Article 11, paragraph 3.

[83] More available at: *Promicanje zdravlja starijih osoba*, http://www.stampar.hr/hr/gerontologija (accessed 15.09.2021).

[84] Social Welfare Act, op. cit., Article 21.

[85] Social Welfare Strategy..., op. cit., pp. 19–20.

[86] Ibidem, pp. 19–20.

[87] Ibidem, pp. 28–29.

[88] Ibidem, p. 29.

the quality of social services for the elderly by educating and re-educating professionals, along with collecting, monitoring and evaluating the “Questionnaire on monitoring the quality indicators in old people’s homes” and providing proposals for measures to improve the quality of healthcare for providers service for the elderly.[89] The Strategy also aims to monitor the health needs and functional abilities of the elderly in the accommodation. It is planned to develop and supplement the manual on active and healthy aging as well as education and re-education for the application of the “14 guidelines for active healthy aging – Croatian model” guide.[90] It is also planned to apply the guidelines of proper nutrition for the elderly and to prepare menu proposals for service providers for older persons, together with the quality control of prepared meals.[91] The strategy also plans regional meetings with service providers for the elderly and training for workers caring for the elderly to strengthen their necessary competencies.[92]

5. Problems faced the by the elderly (with mental disorders)

The range of problems faced by the elderly, including the elderly with mental disorders, is too wide to list, and to analyse them all is not the purpose of this paper; it is a selection of some that the authors consider the most important at this time. In their selection, we took into account the Reports of the Ombudsman of the Republic of Croatia for 2015[93] and 2016,[94] which serve to raise the awareness of the need for a special convention regulating the rights of the elderly as a separate entity, following the rights already guaranteed by regional conventions, one of which came into force this year.

5.1. Accommodation in homes for the elderly and infirm and other social care services for the elderly

The Ombudsman’s report for 2016 (hereinafter: Report) pointed to the lack of specialised departments for people with Alzheimer’s disease and other

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[89] Ibidem, pp. 29–32.

[90] Ibidem.

[91] Ibidem.

[92] Ibidem, p. 32.

[93] Report of the Ombudsman of the Republic of Croatia for 2015 [Izvješće pučke pravobraniteljice RH za 2015]. Available at: https://www.ombudsman.hr/hr/download/izvjesce-pucke-pravobraniteljice-za-2015-godinu/?wpdmdl=4741&refresh=6322ec538e0891663233107 (accessed 15.09.2021).

[94] Report of the Ombudsman of the Republic of Croatia for 2016 [Izvješće pučke pravobraniteljice RH za 2016]. Available at: https://www.ombudsman.hr/hr/download/izvjesce-pucke-pravobraniteljice-za-2016-godinu/?wpdmdl=4743&refresh=6322ec483f6b21663233096 (accessed 15.09.2021).

dementias in homes for the elderly and infirm in the Republic of Croatia.[95] People with Alzheimer's disease and other dementias are placed in inpatient geriatric wards in these institutions.[96] Furthermore, the unavailability of certain social welfare services, such as home assistance, counselling or residence (duly prescribed by the Social Welfare Act) to persons in certain, mostly rural areas, is discussed. Inspections of social service providers for the elderly in 2016 resulted, among other things, in the imposition of measures in private homes to maintain hygiene and cleanliness of the premises.[97] The report further points to the insufficient number of inspections of homes for the elderly, caused primarily by the undercapacity of the responsible service.[98]

Inadequate care for the users of the Nursing Home for the elderly was the cause for the Dondov v. Bulgaria case.[99] The ECHR found, *inter alia*, a violation of the right to life under Article 2 of the Convention due to the action of the authorities which did not secure an effective inquiry to establish the facts surrounding the disappearance of Ms Stoyanova (the applicant's mother), who suffered from Alzheimer's disease, from the nursing home, which made it was impossible to determine the liability of those responsible for her disappearance.[100]

The ECHR also dealt with the issue of involuntary placement of a person in a nursing home. In the case of H.M. v. Switzerland,[101] the court found that there had been no violation of the right to liberty and security under Article 5 of the Convention regarding the involuntary placement in a nursing home of an applicant who had previously lived in unsuitable conditions and together with her son refused help in ensuring suitable conditions in their own home.

The replacement of the social assistance service during the night (for toileting) by using incontinence pads was the subject of a decision of the ECHR in McDonald v. the United Kingdom.[102] The applicant's care plan of 24 July 2007 indicated that the applicant needed assistance with toileting when it was required during

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[95] Ibidem, p. 78.

[96] Ibidem.

[97] Ibidem, p. 80.

[98] Ibidem.

[99] Case of Dodov v. Bulgaria, European Court of Human Rights, Application No. 59548/00. Available at: https://hudoc.echr.coe.int/eng#{%22appno%22:[%2259548/00%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-84438%22]} (accessed 28.10.2020).

[100] Ibidem, paragraphs 97–98.

[101] Case of H.M. v. Switzerland, European Court of Human Rights, Application No. 39187/98. Available at: https://hudoc.echr.coe.int/eng#{%22appno%22:[%2239187/98%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-60169%22]} (accessed 28.10.2020).

[102] Case of McDonald v. the United Kingdom, European Court of Human Rights, Application No. 4241/12. Available at: https://hudoc.echr.coe.int/eng#{%22appno%22:[%224241/12%22],%

the night.[103] Just over a year after the adoption of the care plan, on 21 November 2008, the local authority decided to replace it by providing the applicant with incontinence pads she had to wear overnight in lieu of night-time care. The revision of the care plan itself did not take place until 4 November 2009, when it was decided that incontinence pads were a practical solution to the applicant's problems. The court found a violation of the right to respect private and family life under Article 8 of the Convention for the period between 21 November 2008 and 4 November 2009, referring also to the decision of the United Kingdom Supreme Court which had previously ruled that, although it did not find a violation of Article 8 of the ECHR, if found, it would be between 21 November 2008 and 4 November 2009, when the applicant's proposed care provision was not "in accordance with the law".[104] The Supreme Court of the United Kingdom, therefore, argued that the violation of the law was not of such intensity as to cause a breach of Article 8 of the Convention, but not that there had been no violation. The ECHR, as already stated, ruled that there had been violations. Importantly, the ECHR also acknowledged that from 4 November 2009 onwards, there was no doubt that the interference was "in accordance with the law". The court stated that, from that moment on, the interference on the rights protected by Article 8 of the Convention pursued a legitimate aim, namely the economic wellbeing of the State and the interests of the other care-users. Replacing night care with incontinence pads was "necessary in a democratic society" and proportionate to the legitimate aim pursued.[105] This decision is in line with the previous jurisprudence of the ECHR, which established a wide margin of appreciation for individual countries in issues of general policy, including social, economic and healthcare policies.

5.2. Healthcare for the elderly in rural areas

The quality of healthcare, which is often below the level of urban parts of the Republic of Croatia, is a problem of the rural population, to whom even a family doctor is often inaccessible.[106] The right to healthcare is prescribed in Article 3 of the Healthcare Act, which states that "everyone shall be entitled to healthcare and to the possibility of attaining the highest level of health [...]".[107]

22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-144115%22]} (accessed 28.10.2020).

[103] Ibidem, paragraph 8.

[104] Ibidem, paragraph 24.

[105] Ibidem, paragraph 53.

[106] Social Welfare Strategy..., op. cit., p. 87.

[107] Law on Health Care [Zakon o zdravstvenoj zaštiti]. *Official Gazette of the Republic of Croatia "Narodne novine"*, Nos. 150/08, 71/10, 139/10, 22/11, 84/11, 154/11, 12/12, 35/12, 70/12, 144/12, 82/13, 159/13, 22/14, 154/14, and 70/16. The Law was amended (*Official Gazette*

It is necessary to provide people in rural areas with a higher level of healthcare to guarantee, at least approximately, the same conditions as for other residents of the Republic of Croatia, also taking into account the fact that due to the emigration of younger population from rural areas the elderly are often left to care for themselves. This problem is not only restricted to the Republic of Croatia, and addressing it through a separate Convention on the Rights of the Elderly would certainly encourage individual states to confront it.

5.3. The elderly (with mental disabilities) and criminal proceedings

In 2015, the share of persons over 60 years of age in the prison population of the Republic of Croatia was 7.98%.[108] Elderly people in prisons are housed together with the general population, and no prison has an adapted infrastructure for them, nor are programmes in the prison system being designed with older people in mind,[109] although The Execution of Prison Sentence Act[110] in Article 74, paragraph 1 explicitly provides that "accommodation of inmates has to meet health, hygienic and spatial standards and be appropriate to the climate", while Article 75 provides that "inmates suffering disability shall be granted accommodation appropriate to the kind and degree of their disability". Furthermore, Article 78, paragraph 1 of the same Act prescribes that to the inmates shall be offered meals the quality and quantity of which shall satisfy the requirements of nutrition and hygiene and shall be appropriate, *inter alia*, to the age of the inmates.

Inappropriate conditions of imprisonment were the subject of the ECHR's Farbtuhs v. Latvia judgement.[111] The applicant, convicted of crimes against humanity and genocide, was sentenced to five years' imprisonment. His health condition was critical, suffering from, among other things, spondylosis with deformation

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of the Republic of Croatia "Narodne novine", Nos. 100/18, and 125/19), but the provision stayed the same, now regulated in the Article 5.

[108] Report on the condition and operation of penitentiaries, prisons and educational institutions for 2015 [Izvješće o stanju i radu kaznionica, zatvora i odgojnih zavoda za 2015. godinu], Ministry of Justice of the Republic of Croatia, Prison System Directorate. Available at: http://vlada.gov.hr/UserDocsImages//Sjednice/2016/14%20sjednica%2014%20Vlade//14%20-%209.pdf (accessed 30.10.2017).

[109] Social Welfare Strategy..., op. cit., pp. 155–156.

[110] Prison Execution Act [Zakon o izvršavanju kazne zatvora]. *Official Gazette of the Republic of Croatia "Narodne novine"*, Nos. 128/99, 55/00, 59/00, 129/00, 59/01, 67/01, 11/02, 190/03, 76/07, 27/08, 83/09, 18/11, 48 / 11,125 / 11, 56/13, and 150/13.

[111] Affaire Farbtuhs c. Latvia, European Court of Human Rights, Application No. 4672/02. Available at: https://hudoc.echr.coe.int/eng#{%22display%22:[2],%22languageisocode%22:[%22FRE%22],%22appno%22:[%224672/02%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-67652%22]} (accessed 28.10.2020).

of the spine, osteoarthritis, high blood pressure and chronic cardiac insufficiency, and required constant care and regular treatment. Regardless, he was sent to serve his sentence, where he was admitted to the prison hospital immediately upon arrival. The applicant remained in the prison hospital for one year, nine months and 13 days until his release, after finding, *inter alia*, that he had contracted two further illnesses while in prison, namely diabetes mellitus and irregular blood supply to the brain. In its decision, the court emphasised the fact that the applicant had started serving his prison sentence at the age of 84, paraplegic and disabled to the point of being unable to attend to most daily tasks unaided. In particular, he was unable to get up, sit down, move, get dressed or washed without assistance.[112] The Court pointed out that when national authorities decide to imprison such a person, they have to be particularly careful to ensure that the conditions of detention are consistent with the specific needs arising out of the prisoner's infirmity.[113] The applicant was looked after and assisted either by members of staff from the infirmary or, outside working hours, voluntarily, by fellow prisoners.[114] Having regard to the circumstances of the case, the Court found that, in view of his age, infirmity and condition, the applicant's continued detention was not appropriate. The situation in which he had been put was bound to cause him permanent anxiety and a sense of inferiority and humiliation so acute as to amount to degrading treatment within the meaning of Article 3 of the Convention.

The detention of an elderly person was the subject of the Vasileva v. Denmark case.[115] On a public bus, the 67-year-old applicant was accused of travelling without a valid ticket. When the ticket inspector was about to issue her a penalty fare, she refused to disclose her identity and the police were consequently called. They requested that the applicant give her name and address, and since she refused again, she was arrested. According to police reports, during the detention the applicant was regularly attended to and called upon through the intercommunication system but that each approach was met with "screaming" and continuing refusal to reveal her identity.[116] Twelve hours after her detention, the applicant revealed her identity and was released, after which she was immediately hospitalised for three days diagnosed with high blood pressure.[117] Danish law did not specify the length of detention for identification purposes, except the fact that it should

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[112] Ibidem, paragraph 56.

[113] Ibidem, paragraphs 51–52.

[114] Ibidem, paragraph 41.

[115] Case of Vasileva v. Denmark, European Court of Human Rights, Application No. 52792/99. Available at: https://hudoc.echr.coe.int/eng#{%22appno%22:[%2252792/99%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-61309%22]} (accessed 28.10.2020).

[116] Ibidem, paragraph 11.

[117] Ibidem, paragraphs 8–9.

be brief.[118] The Court did not find a violation of the right to liberty and security under Article 5 of the Convention in respect of the applicant's detention for identification purposes, taking into account her age and health, but also the fact that the police had estimated that she was approximately 60 years old and that they could not be aware she suffered from high blood pressure. However, the Court found a violation of Article 5 of the Convention, having regard to the period of detention, the fact that the applicant's failure was a minor offence, and taking into account the applicant's circumstances, finding that the duration of detention violated the principle of proportionality.[119]

The ECHR decided on the placement of elderly people with physical and/or mental disabilities in prison in various cases, most often finding a violation of the prohibition of torture under Article 3 of the Convention.[120] It is important to note that the health problems must be of a certain (sufficiently serious) intensity for a prison sentence unsuitable for such a person to constitute a violation of Article 3 of the Convention.

5.4. Deprivation of legal capacity

Progress in depriving a person of legal capacity was made in the legislation of the Republic of Croatia with the adoption of the new Family Law in 2015, which also implemented the decision of the ECHR in the case of X. and Y. v. Croatia.[121] The applicants, mother (X) and daughter (Y), lived together until 2006 when X, the mother of the other, was placed in a home for the elderly and infirm due to her age and illness. A special mandatary[122] was assigned to her by the Social Welfare Centre based on the fact that, due to her age and health condition, she could not represent her own interests in the process of placement in a home. The opinion of the Social Welfare Centre and the special mandatary was that Y, the daughter of X, could not take care of her mother adequately due to her health condition – muscular dystrophy. A psychiatric examination based on the previous medical findings and a conversation with the patient found that X was an old and infirm person suffering from psycho-organic changes and dementia and required all-day

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[118] Ibidem, paragraph 23.

[119] Ibidem, paragraphs 41–43.

[120] Affaire Contrada c. Italy (No. 2), European Court of Human Rights, Application No. 7509/08. Available at: https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-140772%22]} (accessed 28.10.2020).

[121] Case of X. and Y. v. Croatia, European Court of Human Rights, Application No. 5193/09. Available at: https://hudoc.echr.coe.int/eng#{%22appno%22:[%225193/09%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-107303%22]} (accessed 28.10.2020).

[122] Cf. Article 241 of the Family Law, op. cit.

care and nursing by another person. The special mandatary suggested that X should be deprived of her legal capacity and that a mandatary should be appointed, noting that Y often behaved strangely, showing dissatisfaction, and locked herself in the home and refused food. The process of deprivation of legal capacity began in 2008, and her niece was appointed the mandatary of X. Y complained that neither she nor her mother X had been served with a decision on deprivation of legal capacity, and that the said niece was not an appropriate mandatary, instead it should have been her. The head nurse at the nursing home, on the other hand, confirmed that X had received the decision and confirmed the receipt with her signature. In the meantime, during the proceedings, X authorised Y to represent her in the inability proceedings, which she confirmed by signing. During the procedure, Y argued that the psychiatric examination should be dismissed as it was based on old medical findings and a 20-minute conversation with X, in the afternoon when she was disoriented by medications. She also demanded the disqualification of the judge for bias. Her claims were rejected because the president of the court stated that she was not a party to the proceedings. The court deprived X of her legal capacity and appointed her niece as her mandatary. Neither X nor Y was served with the decision. X demanded from the municipal court, which deprived her of her legal capacity, to deliver the court's decision to Y, which she signed with her full name, but did not receive a reply.

Shortly after depriving X of her legal capacity, the Social Welfare Centre began proceedings to deprive Y of legal capacity. In its submission to the municipal court, the Social Welfare Centre stated her condition of muscular dystrophy, her behaviour after placement of her mother in home, history of psychiatric hospitalisation for reactive depressive psychosis (12 years earlier), possessive behaviour towards the mother (head nurse in the nursing home where X was housed made an official note of Y's behaviour – describing her constant remarks about the care her mother X was receiving, interference in staff affairs, visits twice a day and staying for more than two hours), etc. In the process, the court received an opinion of a psychiatric expert based on a telephone conversation with Y, who suggested complete deprivation of legal capacity. In the proceedings, she was heard in court, where she claimed that she was capable of taking care of her rights and interests and that she herself could not imagine what the consequences would be for her if she were deprived of her legal capacity. The psychiatric expert submitted another finding later in the proceedings in which he reiterated his previous opinion. The finding was not based on a new conversation with Y. At the time of the ECHR judgment, the proceedings for deprivation of Y of legal capacity were still pending.

In its judgment, the ECHR pointed out that it is the court, and not the psychiatrist, that should assess all the evidence and deprive or not deprive a person of legal capacity. Referring to the previous judgment in the case of Shtukaturov

v. Russia,[123] the ECHR pointed out that the court, in cases where it decides on matters that may have far-reaching consequences for the personal life of the person concerned such as deprivation of legal capacity, should generally have personal contact with the person concerned. The verdict points out that, although it was stated in the report of the psychiatric expert that meaningful contact with the first applicant was not possible, the judge of the municipal court conducting the proceedings still should have heard him in person in order to verify if the expert's finding was not arbitrary. Special emphasis is placed on the fact that countries have other, milder measures than deprivation of legal capacity at their disposal when caring for the elderly and infirm, and that deprivation of legal capacity should be used only in exceptional cases. Based on the fact that the mandate by which X authorised Y to represent her in the proceedings was completely ignored by the court, which is why the second applicant was not invited to participate as a party to the proceedings at all, and why her submissions to the court, although extremely important, were not considered at all, and based on the fact that the decision to deprive her of her legal capacity was not delivered to X (nor Y), the Court stated a violation of the right to a fair trial under Article 6 of the Convention.

Regarding the proceedings for the deprivation of legal capacity Y, the Court found a violation of the right to respect for private life under Article 8 of the Convention. The verdict pointed out that in order to initiate the procedure of deprivation of legal capacity of a person, the Centre for Social Welfare should have substantiated the request with convincing facts, and that, in the present case, it was initiated on the basis of the findings of a psychiatrist who spoke to Y only once, by telephone. Given that Centre for Social Welfare, in hearing Y, learned from Y herself that she regularly visited her family doctor, regularly paid bills, etc., the ECHR concluded that there was no evidence to show before or during the proceedings that Y was harming herself or others. Initiation of proceedings to deprive someone of their legal capacity, according to the ECHR, did not comply with legal requirements, had no legitimate aim and was not necessary in a democratic society.

The new Family Law of 2015 changed the procedural provisions on deprivation of legal capacity. Thus, in the old Family Law of 2003,[124] Article 326 paragraph 3 provided that: "The court will endeavour to hear the person about whom

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[123] Case of Shtukaturov v. Russia, European Court of Human Rights, No. 44009/05. Available at: https://hudoc.echr.coe.int/eng#{%22appno%22:[%2244009/05%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-85611%22]} (accessed 28.10.2020).

[124] Family Law [Obiteljski zakon]. *Official Gazette of the Republic of Croatia "Narodne novine"*, Nos. 116/03, 17/04, 136/04, 107/07, 57/11, 61/11, 25/13, and 05/15.

the proceedings are being conducted. If that person is in a psychiatric institution or placed in a social institution, he or she will generally be heard in that institution". Article 498, of the new Family Law (paragraphs 3 and 4) reads:

> (3) The court will hear the person in relation to which the procedure is carried out. If that person is in a psychiatric institution, social welfare institution or is deprived of liberty within the prison system, he or she will generally be heard in that institution. (4) If the court finds that the hearing of a person is not possible due to his/her health condition, he/she shall make a note in the file and state the reasons for not being able to attend the hearing.

The new Family Law certainly provides better procedural rights for people deprived of legal capacity, and these are most often the elderly with mental disorders. Unlike the provision that the court will "seek" to hear the person being tried, which is difficult to understand imperatively in the sense that the court must hear every person, the new provision that "the court will" hear such a person contains such an imperative. In addition, if the court does not hear the person against whom the proceedings are being conducted, it is obliged to explain the reasons in the file. Also, the new Family Law of 2015 explicitly excludes the possibility of complete deprivation of legal capacity,[125] which is in accordance with the Convention on the rights of persons with disabilities.

5.5. The amount of the pension

The ECHR's jurisprudence raises the question of whether an insufficient pension may constitute a violation of the Convention's rights in Larioshina v. Russia[126] and Budina v. Russia Article 3,[127] which prohibits torture and inhuman or degrading treatment or punishment. Both cases were declared inadmissible, however. In its decisions on the inadmissibility of both cases, the ECHR expressed opinions that may indicate future practice and understanding of the ECHR on the issue of pension levels. Thus, in Larioshina v. Russia, the Court pointed out that a completely insufficient amount of pension and other social benefits to which a person is entitled under domestic law could, in principle, raise the issue of a violation of Article 3 of the Convention. However, the Court notes that it is not clear from the facts that the applicant's pension in the present case caused such damage to her physical or mental health that it would reach the minimum level

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[125] Ibidem, Article 234, paragraph 2.

[126] Case of Larioshina v. Russia, European Court of Human Rights, Application No. 56869/00. Admissibility Decision 23 April 2004.

[127] Case of Budina v. Russia, European Court of Human Rights, Application No. 45603/05. Admissibility Decision, 18 June 2009.

of damage necessary for it to be considered a violation of Article 3 of the Convention. In Budina v. Russia, the ECHR took a similar view, but this time using the notion of human dignity, in the sense that the action was dismissed on the ground that it had not been established that the applicant's pension and other social benefits were insufficient to protect the applicant from harm to her mental or physical health or to protect her from being placed in a state of degradation incompatible with human dignity.

As it has already been said, it is precisely the call for human dignity and its preservation that is in focus when we talk about the need to adopt a special UN Convention on the Rights of the Elderly. In its Article 1, the Council of Europe's Convention on Human Rights and Biomedicine also stipulates that parties to this Convention "shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine. Each party shall adopt the necessary measures in its internal law to give effect to the provisions of this Convention". In addition, as prescribed in Article 2, the interests and welfare of a human being shall prevail over the sole interest of society or science.

6. Conclusion: UN Convention on the Rights of the Elderly

According to the estimates offered in 1995 in General Comment No. 6 on the Economic, Social and Cultural Rights of the Elderly, it was clearly stated that "the elderly population is the fastest-growing part of society. By 2015, more than 1.2 billion people will be 60 or older, and more than 70% of them will be in what we currently consider developing countries."[128] Older people, with their particularities, problems and needs whose fulfilment should be enabled, are currently not sufficiently protected by the existing instruments at any level, whether international, regional or national. Positive developments, such as the Inter-American Convention or the African Union Protocol should be commended, but one glance at the list of countries that have enforced/ratified/signed those legal instruments is enough to understand that these instruments, at least for now, are not much more than proclamations, positive, but still only proclamations. At European level, contribution to the rights of the elderly is certainly made by the ECHR, which, although not explicitly mentioned, develops the protection of the elderly throughout the jurisprudence of the European Court of Human Rights.[129] However, the rights of the elderly depend on how the Court interprets the Convention, and it often refrains from engaging in policies on social welfare

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[128] World Health Organisation, *World Health Statistics 2016*, op. cit., paragraph 1.

[129] *Elderly people...*, op. cit.

and healthcare of the signatory states – two areas that are extremely important for the elderly. The European Social Charter (revised) provides a good basis for the rights of the elderly, however, at present, its scope and enforceability are limited.

The international community, regardless of the voices of sceptics, is starting to recognise the need to protect the elderly as one of the most vulnerable groups in society through a comprehensive convention at the international level, primarily through the work of the UN Working Group on Aging. Following the drafting of the convention proposal, which should be based on the solutions of the Inter-American Convention, the African Union Protocol and the European Social Charter, the international community should ensure its widest possible acceptance in order for the elderly to finally have their specific rights clearly defined and recognised. This is the goal whose achievement across the world is long overdue. The Convention on the Rights of Persons with Disabilities, which is "a shift from a medical model of disability to a model based on human rights", should certainly serve as an example.[130] As Doron and Apter further point out:

> Positive potentials nullify the negative ones. We are not arguing that without a convention on the rights of the elderly, their rights could not be guaranteed or that such a convention would be a kind of panacea. However, based on historical experience, we argue that such a convention could be used as a solid foundation for a process that would bring real positive change for older people around the world, especially in regions and countries that lack administrative mechanisms to ensure fundamental human rights for their elderly. Finally, the convention can potentially become a powerful tool for the inclusion and integration of rights into national and international social policies towards the elderly population.[131]

The experiences gained from the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities in improving the position of their target protection groups supports this view. In this regard, however, the following should be emphasised:

> The General Convention (on the Rights of the Elderly) will need to respect human rights standards around the world and will only partially include European specificities. It is worth remembering how the Convention on the Rights of the Child and the 1979 Convention on the Elimination of All Forms of Discrimination against Women have been criticised for ignoring reality in certain

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[130] Kanter, "The United Nations...", op. cit., p. 549.

[131] Israel I. Doron, Itai Apter, "International rights of older persons: What difference would a new convention make to lives of older people?" *Marquette Elder's Advisor* 11 (2010), pp. 367–385.

> parts of the world and for applying Western values to societies of completely different traditions. According to critics, those conventions were blind to multiculturalism and did not include protection of differences within groups.[132]

Therefore, the African Union Protocol should be commended because it specifies the increased need for the protection of the elderly and begins, *inter alia*, with the following words in its preamble: "Taking into account the characteristics of African traditions, values and practices that should inspire and characterise common care and support, respect for older members of society, and the transfer of knowledge to younger groups in society."

The Inter-American Convention on the Rights of the Elderly and the African Union Protocol are to be welcomed and, as we have stated, the rights listed therein should be incorporated into the UN Convention on the Rights of the Elderly, from the point of view of protecting the human rights of the elderly, and not only of providing additional social or medical care. We, therefore, propose that it must contain, *inter alia*, the following provisions:

- the formal legal appearance of old age must depend on average life expectancy in a particular area; it must be revised by the World Health Organisation every five years by a separate document for each territory,
- prohibition of discrimination based on age, with positive discrimination regarding the obligation of countries to create policies tailored to the elderly,
- the right to autonomy,[133] life and dignity in old age,
- special protection for older women,
- special protection of the elderly with disabilities,
- the right to independence and freedom from the influence of others,
- the right to participate in political, social and cultural life,
- prohibition of abuse, torture and cruel, inhuman or degrading treatment, with an emphasis on its prohibition in social and healthcare facilities,
- the right to ownership and property,

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[132] Mikołajczyk, "Is the ECHR...", op. cit., p. 524.

[133] Tomek-Roksandić et al., *Zaštita zdravlja*..., op. cit., p. 219: "Actions that will be important in enabling autonomy include: legislating to protect the rights of older people (for example, by protecting them from elder abuse), supporting older people in becoming aware of and enjoying their rights, and creating mechanisms that can be used to address breaches of their rights, including in emergency situations; providing services that facilitate functioning, such as assistive technologies, and community-based or home-based services; providing mechanisms for advance care planning and supported decision-making that enable older people to retain the maximum level of control over their lives despite a significant loss of capacity; creating accessible opportunities for lifelong learning and growth".

- the right to give informed consent in all proceedings related to health[134] and certain social welfare procedures (e.g. placement in a nursing home),
- the right to healthcare and health, including the right to long-term care,
- the right to freedom of thought and expression,
- the right to work,
- the right to lifelong education,
- the right to adapted access and facilitated mobility,
- the obligation of states to implement programmes aimed at increasing intergenerational tolerance and educating the younger generations about the needs of the elderly, equally valuable members of society,
- establishment of a monitoring mechanism (Committee on the Rights of the Elderly), analogous to the Committee on the Rights of the Child, which oversees the implementation of the Convention on the Rights of the Child, but also for the purpose of achieving intergenerational dialogue and the establishment of the Ombudsman for the Protection of the Rights of the Elderly, and
- the obligation of older people to transfer their knowledge to young people (in relation to the right to work of older people).

All these rights can be prescribed at the regional level, and this is an initiative which the Republic of Croatia should advocate within the European Union and the Council of Europe, as was done by the Inter-American Convention and the African Protocol. Of course, each state could protect and guarantee more rights to the elderly than stipulated in the Convention.

We should also welcome the latest Lisbon Ministerial Declaration of the UN Economic Council for Europe[135] from 22 September 2017: “A Sustainable Society for All Ages: Realizing the potential of living longer”, which puts active aging at the heart of the approach to older people (t. 5. (b)) and gives guidelines on how to develop the potential that older people have and deserve (t. 12–18). In addition, in its paragraph 35, the Declaration states that it recognises

> the relationship between population aging and economic, social and societal life, environmental development and uphold our commitment to the United Nations 2030 Agenda and the Sustainable Development Goals including ending poverty in all its forms and everywhere, ensuring healthy lives and promoting wellbeing

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[134] Elderly people have their own specific health needs that physicians need to treat with increased care and attention, taking into account the vulnerability of the elderly population, the characteristics of geriatric patients, their age and reduced ability to function independently, depending on the individual elderly person.

[135] 2017 Lisbon Ministerial Declaration: “A sustainable society for all ages: Realizing the potential of living longer”. United Nations Economic Commission for Europe. Available at: http://www.unece.org/fileadmin/DAM/pau/age/Ministerial_Conference_Lisbon/Documents/2017_Lisbon_Ministerial_Declaration.pdf (accessed 30.7.2017).

> at all ages, achieving gender equality, promoting full and productive employment and decent work for all, as well as access to lifelong learning opportunities and making cities and human settlements inclusive, safe, resillienet, and sustainable for people of all ages.

In conclusion, we consider it necessary for the Republic of Croatia, as well as the European Union, to support and actively contribute to the drafting of the UN Convention on the Rights of the Elderly. The benefits that such a convention will bring are exceptional, starting with the protection of the rights and interests of the elderly until the general population is educated about the rights of the elderly. The Convention should have already been enacted, and each day of procrastination means a day of procrastination in providing adequate protection to one significant vulnerable group of our society.

We also must not forget the educational function that the Convention would have in terms of understanding the importance of the position of the elderly in society. The experience given to us by the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities is extremely important and should be applied to the protection of the rights of the elderly.

Unfortunately, the COVID-19 pandemic, when the elderly were the most vulnerable age group, just confirmed how necessary it is to protect the health and rights of the elderly. It must be noted here, however, that during the first wave of the pandemic and the initial lockdown Croatia was able to prevent widespread fatalities among the elderly in nursing homes and hospitals. The enhanced awareness of the need to protect the elderly and intergenerational solidarity that occurred during pandemics in Croatia, especially before the summer months of 2020, make Croatia a good example in protecting the most vulnerable members of society in a time of crisis.

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Hrvoje Jurić

Back to the future: Socialist legacy and recent developments in the Croatian healthcare system

1. Introduction

The aim of this article is to sketch a context in which particular and interesting case of the Croatian healthcare system in transition from the socialist to the post-socialist period could be investigated, in order to better understand not only this particular case, but also the cases which share similar historical experiences with the Croatian one, despite the differences between them.

Since these developments have had, and still have, their reflection in the level of healthcare and public health, if we want to better understand the ongoing trends in the healthcare system in post-socialist countries, which fundamentally affect the life of their citizens, we should analyse this state of affairs at the level of general economic and political changes, and look back at the so-called "resurrection from the darkness of socialism", and *vice versa*: if we want to better understand what has been happening to the people in post-socialist countries in the last thirty years, we should analyse the changes in the sphere of healthcare, probably more than some other phenomena. In this paper, these issues will be discussed using the example of Croatia.

2. Social and political context: Croatia in the post-Yugoslav period

In Croatia today, we can clearly see that the so-called "days of pride and glory" (as in the title of the album of the Croatian pop rock band *Prljavo kazalište*)[1] – meaning the first half of the 1990s, when Croatia gained independence – were not so glorious, and that the Croatians should not be uncritically proud of this period, which was characterised by an authoritarian rule of charismatic right-wing leader Franjo Tuđman and his party (Croatian Democratic Union), continuous confrontations with political opponents, "enemies

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[1] Prljavo kazalište, *Dani ponosa i slave*. Croatia Records 1998.

of the state" and "traitors", limited media freedom, unsanctioned rehabilitation of Croatian fascism from the period of the Second World War, normalisation of verbal and physical violence in the public sphere, and – first and foremost – the 1991–1995 war, which was neither wanted nor initiated by Croatian people and Croatian leaders, but which turned many war heroes into war criminals. This war, usually referred to as the "Homeland War", was a catastrophe not only in terms of human lives and material losses, but also in terms of deep and still not cured destruction of the society, its basic structure and cohesion. However, one of the most important aspects of the recent history of Croatia is the rapid process of privatisation or transformation of the formerly "social property" (actually state property) into private property, which mostly proved the thesis we know since Jean-Jacques Rousseau and Pierre-Joseph Proudhon: property (or private property) is theft.[2]

According to that, the post-Yugoslav period of the independent Republic of Croatia since the beginning of the 1990s is characterised by breaking up with the political and economic legacy of Yugoslav socialism, which has implied radical changes in social structure and practices, public morality, and worldview, such as: re-traditionalisation, re-conservatisation, re-catholicisation and related clericalisation of the public, social and political sphere. These processes have been led by the leading political forces of the country, especially its ruling governments.[3]

Nevertheless, the Catholic Church and its leaderships played a very important role in all these developments, profited largely from such situations and never seriously criticised right-wing politicians and so-called "controversial businessmen" as the main protagonists of the Croatian "transition period". Since the beginning of the 1990s, ideological hegemony, nationalism and its own material interests have always been much more important to the Catholic Church in Croatia than the Gospel and the Catholic social teaching. The Catholic Church in Croatia, in its "anti-communist Reconquista", adopted, unfortunately, the logic of the ruling political structures or even co-produced this logic. According to this logic, the proper identity ("to be a Croat", "to be a Catholic"),

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[2] Jean-Jacques Rousseau, "Discourse on the origin and the foundations of inequality among mankind". In: idem, *The Social Contract and The First and Second Discourses*. New Haven, London 2002, p. 113; Pierre-Joseph Proudhon, *What is Property?* Cambridge 2002.

[3] By 2020, the Republic of Croatia had 15 governments and only three of them were not governments of the Croatian Democratic Union, a conservative centre-right party, and its allies. Other three governments – eight years altogether – were governments of the Social Democratic Party, successor of the former League of Communists of Croatia, and its allies, although it is important to note that the Social Democratic Party of Croatia thoroughly broke up with its socialist/communist past and today it is closer to the interests of business than to the interest of workers, while at ideological level uses moderate liberal vocabulary.

as well as the proper worldview related to that, have been identified with accepting and promoting specific political views (conservative, right-wing ones) and specific economic views under the flag of "transition to capitalism". "To be a Croat" and "to be a Catholic" means to be obedient towards the self-proclaimed authorities and to act dutifully in the best interest of the State and the ethnically defined Nation. This interest is, naturally, defined by those who hold political and economic power. The interests of so-called "ordinary people", the majority of the population, including some especially vulnerable minorities, do not fit into this framework. There are winners, there are losers, but the losers mostly do not know that they are losers, because they are permanently manipulated by the elites, which possess "golden calves" of the Nation and the State.

Some significant traits of the previously mentioned developments can also be found in the sphere of healthcare. They will be briefly presented using two examples: first, the tendency to restrictive legislature and policies regarding abortion, including promotion of "conscientious objection" in gynaecology and reproductive medicine; and, second, crawling commercialisation and privatisation of healthcare services and the diminishing quality of healthcare.

3. First example: the issue of abortion

Regarding abortion, it should be said that in Croatia the 1978 "Law on Medical Measures for Exercising the Right to Free Decision about Giving Birth to Children" (with some changes adopted in 1986, 1989 and 2009)[4] is still in force, which is, in common terminology, "liberal" and emancipatory-oriented regarding women's reproductive rights. The fact that no government in the last thirty years has proposed a new law indicates that there is no real political will to draft a new, restrictive law on this controversial issue, as requested by some conservative and right-wing civic initiatives and political parties as well as the Catholic Church.[5] However, the issue of abortion is a usual topic in political bickering, especially during election campaigns, but with a lot of hypocrisy and opportunism, just as in the very medical practice, because

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[4] Law on Medical Measures for Exercising the Right to Free Decision about Giving Birth to Children [Zakon o zdravstvenim mjerama za ostvarivanje prava na slobodno odlučivanje o rađanju djece]. *Official Gazette of the Republic of Croatia "Narodne novine"*, Nos. 18/78, and 88/09.

[5] Marina Škrabalo, Hrvoje Jurić, "Utjecaj Katoličke crkve u Hrvatskoj na politiku reproduktivnih i seksualnih prava i zdravlja" [Influence of Catholic Church in Croatia on the Policies of Reproductive and Sexual Rights and Health]. In: Simona Goldstein (ed.), *Otvorenost društva – Hrvatska 2005*. Zagreb 2005, pp. 166–198.

it is a "public secret" that many public opponents of the right to abortion are performing (or performed previously) abortions, if not in public healthcare institutions (as "conscientious objectors"), then in private clinics. (Regarding that, the ongoing public debates on "conscientious objection" in medicine and related professions, a topic which is not strictly nor satisfactorily regulated in relevant Croatian legislation, should also be of interest when discussing the previously mentioned trends.)

Significant statements were made by three Croatian politicians – all of them physicians and members of the Croatian Democratic Union. In 2015 Ante Ćorušić, a gynaecologist and at one point a candidate for the position of health minister, said that: "The modern Croatian state cannot be a slave to a law passed during a totalitarian, communist regime. We need to change and civilise it, to improve the procedure, in the interest of the health of women and unborn children."[6] Furthermore, Ćorušić said: "I was one of the experts who said that human life begins by merging the female and male gametes; it is a proven scientific fact. If we look legislatively and biologically, abortion is an agreed form of a violent interruption of human life, we must be aware of this fact, it is a bioethical truth."[7] However, he stated that "an absolute ban on abortion is out of the question, because 'we need to be aware of what society we live in', but there must be a better and more ethical procedure towards the unborn child".[8]

In 2016 Dario Nakić, the health minister, said: "I am for life, but I will never be for abortion to be legally banned. I think that every woman should consult an expert before deciding on such an act."[9] His successor to the position of the health minister (2016–2020), Milan Kujundžić, stated in 2016: "Personally, I am against abortion, but also against the ban, because it does not bring a solution, but only more lost lives, both of children and mothers. It is necessary to educate girls; also, psychological and material support of the state is needed."[10] Very firm when they are in opposition, very mild when they are in power. Very firm in worldview

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[6] Hina, "HDZ-ovac Ante Ćorušić: 'Trebalo bi promijeniti ime Ministarstva zdravlja, a iz kanadskog modela preuzeti samo decentralizaciju'". *Jutarnji list* (29.12.2015). Available at: https://www.jutarnji.hr/vijesti/hrvatska/hdz-ovac-ante-corusic-trebalo-bi-promijeniti-ime-ministarstva-zdravlja-a-iz-kanadskog-modela-treba-preuzeti-samo-decentralizaciju-201973 (accessed 29.02.2020).

[7] Hina, "HDZ-ovac Ante Ćorušić...", op. cit.

[8] Ibidem.

[9] Ivana Rimac Lesički, "Pušač koji doživi infarkt i nastavi pušiti plaćat će skuplje osiguranje". *Večernji list* (26.01.2016). Available at: https://www.vecernji.hr/vijesti/pusac-koji-dozivi-infarkt-i-nastavi-pusiti-placat-ce-skuplje-osiguranje-1054926 (accessed 29.02.2020).

[10] Hina, "Kujundžić: 'Osobno sam protiv abortusa, ali i protiv zabrane, jer ne donosi rješenje'". *Večernji list* (20.10.2016). Available at: https://www.vecernji.hr/vijesti/kujundzic-osobno-sam-protiv-abortusa-ali-i-protiv-zabrane-jer-ne-donose-rjesenje-1122477 (accessed 29.02.2020).

debates, very mild when in executive positions. This could be a summary of conservative politics regarding abortion in Croatia. But none of the above prevented the persons mentioned above (as it did not prevent their party) from supporting conservative civic initiatives, such as the NGO “In the Name of the Family” (“U ime obitelji”), in various ways.

In October 2016 this NGO, “In the Name of the Family”, submitted to the Constitutional Court of the Republic of Croatia a request for a review of the constitutionality of the “Law on Medical Measures for Exercising the Right to Free Decision about Giving Birth to Children” because, in their opinion, an abortion could be performed only if the mother’s life was endangered. They referred to Article 21, paragraph 1 of the Constitution of the Republic of Croatia, which states that every human being has the right to life, then to the Constitution’s Article 14, which states that everyone in the Republic of Croatia has rights and freedoms, regardless of his/her gender or other characteristics, and to Article 23, paragraph 1, which states that no one may be subjected to any form of ill-treatment or, without his/her consent, to medical or scientific experiments.[11] In March 2017, the Constitutional Court of the Republic of Croatia rejected that request, i.e. concluded that the incriminated law is not unconstitutional. The Constitutional Court also ordered the Croatian Parliament to pass a new law on the issue within two years. However, this did not happen until the spring of 2019, nor later.

The issue of abortion (similar to the issue of medically assisted reproduction, which is also a matter of intensive public debates in Croatia) is not only a gender issue, i.e. an issue of women’s reproductive and human rights, but also a class issue. Because many women, especially in smaller communities, are unable to exercise the right to abortion in public healthcare institutions, either because public healthcare institutions do not perform abortions (due to an excessive use of the right to “conscientious objection” by physicians) or because women are under pressure from their communities and have to ask private clinics for this service. The consequences of that are, at least, twofold: the discrimination of women of lower social status and prosperity of the private healthcare segment. Some counter-initiatives (especially the feminist ones) have warned about key issues and insisted on public debates about it, which has somewhat diversified public discussions, but at the moment conservative agents seem to have an advantage in shaping public opinion.

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[11] Constitution of the Republic of Croatia [Ustav Republike Hrvatske]. *Official Gazette of the Republic of Croatia “Narodne novine”*, Nos. 56/90, 135/97, 8/98, 113/00, 124/00, 28/01, 41/01, 55/01, 76/10, 85/10, and 5/14.

4. Second example: the issue of commercialisation and privatisation of healthcare

The class aspect of the issue of abortion introduces us to the problems of healthcare system in general, because this system in Croatia is less and less favourable to citizens of lower social status,[12] and thus less and less socially oriented, i.e. more and more oriented to the interests of "private initiative" and capital in the sphere of public good, including not only healthcare, but also education, urban planning, etc. All of that – often explicitly – takes place under the auspices and with the help of declared traditionalist and conservative political and social agents.

Although, at first sight, this state of affairs, which joins "hyper-capitalism" and "hyper-Catholicism", could seem paradoxical, if we look at the underlying ideology it should seem only logical. Namely, in Croatia we can observe an increasing influence of the American type of neoconservatism (promoted by several civil movements, NGOs and political parties), which joins neoliberal economic-political views and Christian fundamentalist views on sexuality, reproduction and family.

If we monitor the situation under these premises, the logic of these parallel developments is clear, and the only paradox could be found in the fact that neoconservative trends in economic-political matters are strongly opposed to traditional Croatian conservatism, which has been rooted in Christian Catholic social views of peasants and workers, and much closer to socialist attitudes and policies than to neoliberal-capitalist ones.

However, currently in Croatia there is no strong opposition to such developments. Truly left and left-liberal initiatives, non-governmental organisations and political parties (which are oriented towards human rights, individual civic rights and the commons) are so weak and, even more importantly, so separated and dispersed that, currently, we cannot expect forming a strong civil movement which would systematically and continuously fight the previously mentioned dangerous trends.

On the other hand, there are the cunning politics of neo-conservative agents; manipulative politics of right-wing political parties and governments, and calculative and opportunistic politics of nominally social-democratic political parties and governments; as well as general apathy and passivity of citizens of any political orientation, together with a rapid erosion of the public sphere, including public media. All of that make these dangerous trends so strong and so "fluent".

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[12] Ana Bobinac, *Pristup zdravstvenim uslugama u Hrvatskoj: Policy izvještaj* [Access to Health Services in Croatia: Policy Report]. Zagreb 2017. Available at: https://www.cms.hr/system/publication/pdf/95/Pristup_zdravstvenim_uslugama_u_Hrvatskoj_.pdf (accessed 29.02.2020).

One of the usual ways of "normalising" these radical changes (for example in the sphere of healthcare) is to portray these changes as a "necessity" and, moreover, as a "progress" in adjusting the Croatian healthcare system and services to some European and global scientific and social trends. However, the question should be raised: Adjusting to what, actually? The answer is quite obvious: adjusting to non-social (if not anti-social) policies and politics, according to the pattern of the American (meaning the U.S.) model of deregulation of all the public services aimed at all citizens, regardless of their social status. Nevertheless, these trends should be interpreted as a *regression* in terms of human and civil rights, especially those of women and/or citizens of lower financial and social status.

This is the meaning of the title of this paper, "Back to the future": the obvious regression is usually presented as a progress. The intention of this paper is not to glorify Yugoslav socialism, because it was the system (and the state) which was burdened with severe systematic problems and practices (for example, regarding civic freedoms), but, in the sphere of the healthcare, the socialist legacy should be preserved, and not diminished or eradicated.

Criticisms of the Yugoslav-socialist healthcare system, such as Donna E. Parmelee's 1985 paper,[13] should be taken into account because they were probably justified in "real-time", as they pointed to the shortcomings of that system, which could be enhanced. However, from today's perspective, what was deficient in socialism (in terms of healthcare) today either does not exist or is radically threatened.

What did socialism offer in the sphere of healthcare (in Yugoslavia and other socialist countries)? The following could be mentioned: socially oriented healthcare system; maximum possible investment into the healthcare system; maximum possible quality of the healthcare services; orientation towards public health (or people's health); non-discriminative approach to healthcare services; emancipatory policies in the sphere of healthcare, oriented towards vulnerable groups and individuals. On the other hand, the healthcare system of today's neoliberal capitalism, which is being increasingly adopted in post-socialist countries such as Croatia, is exclusive and discriminative. It asks for minimal possible (public) investment into healthcare services, or maximum possible profit made from minimal possible investment, and does not care about the quality of general (public) healthcare, while it is treating citizens and individuals as (potential) patients, and patients as customers, just as in any other sector of social life which is aimed to generate profit. (Fortunately, there are several competent and prolific

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[13] Donna E. Parmelee, "Whither the state in Yugoslav health care?". *Social Science and Medicine* 21 (1985), pp. 719–728.

authors in Croatia who continuously monitor, analyse and critique these trends, such as Nataša Škaričić and Ana Vračar.[14])

When confronting "socialist" and "capitalist" (or "old" and "new") approach to the issues of public health and healthcare – using the example of Croatia – we should not rely only on the difference between "Yugoslav-socialist" and "post-Yugoslav"/"post-socialist" approaches, because the "Yugoslav-socialist" approach to the healthcare was founded on the older grounds, primarily on the legacy of the Croatian/Yugoslav physician, public educator, and social worker Andrija Štampar (1888–1958), who assisted, between the two World Wars and afterwards, in inventing and promoting the concepts of public health and socially oriented medicine, as well as related practices and policies, including the activities in establishing the World Health Organisation.[15]

If we today want to save the very idea of public health and socially oriented medicine, we should stick to the collective memory of not merely romantically presented "better past", but also specific achievements from the past, and re-think the ethically connoted concepts of life, good life, health, public health, community, society and sociability, which fortunately are being revived in some branches of recent bioethical discussions. In that sense, Štampar's ideas and "ideology", and his analyses, could be a starting point, such as his sentences written as early as in 1919:

> In capitalist economy, a man can own an economic value, but he is not an economic value in himself; if he is not using his labour force, or he loses it, he is nothing more than water and air. [...] The entire social life is adjusted to the idea that the masses of human beings should be destroyed for the love of an illusory wealth [...], forgetting at the same time that this economy benefits only some people.[16]

Not only the fact that this is a quote from Štampar's text on health policy, but also his entire, lifelong engagement proves that he saw capitalism as a threat to health and public health, and that he tried continuously to save the sphere

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[14] Series of articles by Nataša Škaričić, published in the Croatian online magazine *Lupiga* (https://lupiga.com), and by Ana Vračar, published in the Croatian online magazine *Bilten* (https://www.bilten.org).

[15] Željko Dugac, Stella Fatović-Ferenčić, Luka Kovačić, Tomislav Kovačević, "Care for health cannot be limited to one country or one town only, it must extend to entire world: Role of Andrija Štampar in building the World Health Organisation". *Croatian Medical Journal* 49 (2018), pp. 697–708; Stella Fatović-Ferenčić, Martin Kuhar, "'Imagine all the people': Andrija Štampar's ideology in the context of contemporary public health initiatives". *Acta Medica Historica Adriatica* 17 (2019), pp. 269–284; Sanja Špoljar Vržina, "Neoliberalno 'zdravlje', globalna bolest i štamparovska medicina" [Neoliberal "health", global illness and Štampar's medicine]. *Društvena istraživanja* 17 (2008), pp. 999–1021.

[16] Andrija Štampar, "O zdravstvenoj politici" [On Health Policy]. *Jugoslavenska njiva* 3, 29–31 (2019), p. 2. Quoted in: Špoljar Vržina, "Neoliberalno 'zdravlje'", op. cit., p. 1011.

of health and public health from profit-oriented economic power. Both Štampar's and socialist-Yugoslav visions of public health and related efforts were directed against such trends that we are facing today.

5. Instead of conclusions: questions for further research

How did it happen that the legacies of Andrija Štampar and the Yugoslav socialist system of healthcare were forgotten and started to vanish in today's Croatia? In order to answer this question, we should investigate the recent trends by looking for the underlying ideology and, on this basis, to recognise particular problems and articulate them in a historical perspective, and to continuously act – with a tendency to radically reform the very conditions of performing politics – according to principles of the rights of the individual and the common good, which are not mutually exclusive, but compatible concepts. Possibly, this could be the beginning of resolving the ongoing problems of destruction of the healthcare system and the entire society, which we are mentally adapting to, to such an extent that they are becoming a normal state of affairs and, accordingly, an invisible catastrophe.

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Vanessa Marie Zeeb

Healthcare for persons seeking international protection in Germany – Psychiatric and psychotherapeutic care

1. Introduction

This part examines the main problems concerning access to the German healthcare system for asylum seekers and refugees. The first issue relates to the limited access rules of the AsylbLG (German Asylum Seekers Benefits Act). It is shown that different groups have been categorised together in the AsylbLG even though they have little in common (chapter 2).

According to this Act, health services are limited to the medical treatment of acute illness and pain; the provision of further benefits is left to the discretion of the competent authorities, under the condition that they are necessary to secure basic health needs. Hence, persons covered by the AsylbLG face severe restrictions of their right to healthcare (chapter 3).

This is highly questionable in many ways, as will be demonstrated. Therefore, the legal provisions of German statutory health insurance must be critically evaluated (chapter 4), also in respect of the minimum standards set by the European Union related to access to healthcare (chapter 5).

In this context, the difficulties that arise for asylum seekers, their participation in civil society, healthcare and politics are discussed (chapter 6). This article provides solutions to what needs to be done to counteract the identified difficulties (chapter 7).

2. AsylbLG

The AsylbLG was passed in 1993 with the main goal to drastically reduce previous social assistance benefits for asylum seekers, which had been regarded as an incentive to “abusing” the asylum system, and to establish a specific Act regulating their social rights outside the former Federal Social Assistance Act. As a result, the benefits provided in the social assistance scheme, based on the principle of “individualisation” and aims to provide the minimum of subsistence, were simplified and tailored to the needs of persons with a temporary stay in Germany. This means that individuals seeking asylum were no longer supposed to integrate into society, nor to be able to make a living on their own.[1] Over nearly 30 years of it being in force, the AsylbLG has been amended more than 20 times. The time spans in the legislative process deserve special attention: From 1993 to 2014 (22 years), only eight, mostly smaller, revisions took place. However, after 2015 with a massive increase of immigration into Germany, up to 2020 (six years), the Act so far has been revised 14 times, most of them fundamentally exacerbating the regulations. From now on, different provisions of the AsylbLG will be examined in more detail.

2.1. Personal scope

The personal scope of the AsylbLG covers third-country nationals, who are *de facto* present in the territory of Germany. In addition to that, beneficiaries must fulfill one of the additional requirements, discussed hereafter.

Undocumented migrants without any valid permission (illegal stay) also have access to the benefits of AsylbLG. However, they face various problems in realising their claims. Persons covered by the AsylbLG form a rather heterogeneous group, and this cannot be equated, as will be shown in the sections below.

2.2. Asylum application (from safe countries of origin)

According to section 1 (1) (1) AsylbLG, asylum applicants (from safe countries of origin) have the status of asylum seekers.[2] After arriving in Germany, so-called proof of arrival ("Ankunftsnachweis") is issued; it entitles the holder to benefits arising from the AsylbLG. Due to the fact that the *Ankunftsnachweis* is not a sufficient document, a residence authorisation will be issued after formally applying for asylum. This is not regarded as a residence permit, but a mere approval to stay in Germany as long as the asylum procedures are pending. These proceedings apply to persons from so-called safe countries of origin and from other countries alike, but differ in the duration of the procedure. Currently, all the Member States of the European Union as well as Albania, Bosnia and Herzegovina, Kosovo, Northern Macedonia, Montenegro and Serbia are considered safe countries.

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[1] Draft of a Law to Reorganize Benefits for Asylum Seekers [Entwurf eines Gesetzes zur Neuregelung der Leistungen an Asylbewerber (AsylbLG)]. *Deutscher Bundestag Drucksache*, 12/4451, 02.03.1993, p. 5.

[2] Volker Wahrendorf, "§ 1 AsylbLG". In: Christian Grube, Volker Wahrendorf, *SGB XII. Sozialhilfe mit Asylbewerberleistungsgesetz: Kommentar*. 6th Edition. Munich 2018, margin number 20.

Ghana and Senegal are considered safe countries of origin on the African continent. Asylum seekers from these countries have rather poor prospects of staying in Germany.

2.2.1. Asylum application

Section 1 (1) (1a) AsylbLG was introduced as late as 2019. It covers persons who have just entered Germany and have applied for asylum but do not meet the prerequisites of the other sections. These are cases where an asylum application has been lodged, but no proof of arrival has been issued yet; cf. 2.1.1. This loophole was closed and it was made clear that the statement of the asylum application (and not only with the formal application for asylum at the BAMF [Federal Office for Migration and Refugees]) creates the right to benefits under the AsylbLG.

2.2.2. Airport procedures

Airport procedures are special asylum procedures that are conducted inside the airport for persons who have entered the German territory by aircraft, prior to the decision on entry by border protection services. The procedures usually take up to two days; during the procedure applicants are accommodated on the airport premises, except for necessary medical treatment, which is provided in hospitals.[3] Airport procedures according to section 1 (1) (2) AsylbLG are held at the airports of Berlin-Schönefeld, Düsseldorf, Frankfurt/Main, Hamburg and Munich, because of the possibility to accommodate people there.

2.2.3. Quota refugees

The so-called quota refugees according to section 1 (1) (3a) AsylbLG are allowed to move to Germany in a fixed number (contingent). This applies to refugees who were admitted as part of a humanitarian aid operation or based on visas. In addition, a declaration of acceptance by the Federal Ministry of the Interior (BMI) could be sufficient.

There is no asylum procedure nor any other personal examination taking place, but quota refugees receive a residence permit for humanitarian reasons upon arrival.

According to section 23 (1) AufenthG, this applies to foreigners from specific states or to certain groups of foreigners. The residence permit is granted for reasons of international law or humanitarian reasons or in order to safeguard the political interests of the Federal Republic of Germany.

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[3] Stefan Gerlach, "Das AsylbLG Teil I. Ein Überblick zum aktuell geltenden Asylbewerberleistungsgesetz". *Die Sozialgerichtsbarkeit* 65 (2018), p. 336.

2.2.4. Mass Influx Directive

EU law, in this case, a directive, has a direct impact on the AsylbLG. In section 24 AufenthG, the so-called "Mass Influx Directive" (Directive 2001/55/EC) is implemented, which provides for a residence permit for temporary protection. Protection is granted on the basis of a decision of the Council of the EU. The main goal is the Europe-wide reception of persons from war and civil war regions. Due to a statement of the EU Member States, the Mass Influx Directive is currently not applicable,[4] which is not understandable. After 2014, many states, especially from the south of Europe, requested the activation of the solidarity mechanism of the Directive in order to achieve a more sustainable division of the refugees Europe-wide. Therefore, due to the non-application of the Directive, this part of section 1 (1) (3a) AsylbLG has currently no meaning.

2.2.4.1. Person required to leave the country (non-enforceable)

Section 1 (1) (3b) AsylbLG applies to persons who are required to leave the country, as long as this requirement is non-enforceable. They receive a residence permit if their further temporary presence in the Federal territory is necessary on urgent humanitarian or personal grounds or due to substantial public interests. Urgent humanitarian or personal reasons can be the stay to perform a surgery that could not be guaranteed (to a sufficient extent) in the country of origin, the temporary care of sick relatives or regulating important personal matters. It is assumed that public interest is when a foreign person is required as a witness or if they cooperate with the authorities in criminal investigations and, if necessary, are even included in a witness protection programme. However, this is not intended to provide a legal basis for permanent residence in Germany, and that is why the residence permit is usually granted for up to six months only.

2.2.4.2. Person enforceable required to leave the country

Section 1 (1) (3c) AsylbLG refers to foreigners who are enforceably required to leave the country, but are not able to leave, either in law or in fact, for example because of their inability to travel for medical reasons, missing passport or interrupted traffic connection to the destination country. This group can only be assigned to the scope of application of the AsylbLG if their deportation has been suspended for not longer than 18 months. They receive a residence permit. This regulation is intended to serve as a basis for decisions in cases of hardship, which

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[4] Answer given by Mr Avramopoulos on behalf of the Commission. European Parliament, Question reference: E-016015/2015. Available at: http://www.europarl. europa.eu/doceo/document/E-8-2015-016015-ASW_EN.html (accessed 06.12.2021).

enables “a flexible application of the law that takes account of the requirements of the individual case”.[5] There are time limits, restrictions and requirements.

The conditions for the preclusion of deportation have recently been tightened, especially regarding mental problems. It is necessary to present a so-called qualified medical certificate; furthermore, PTSD is no longer recognised as a serious illness.[6]

2.2.4.3. Suspension of deportation

If deportation is suspended, a temporary permission to stay in the country is issued, referred to as “Duldung”, which means that the stay is merely tolerated. Regularly, only adults are entitled to these benefits in accordance with section 1 (1) (4) AsylbLG. However, in very few exceptional cases, children and adolescents may also be entitled to these benefits. Reasons for suspension of deportation may include the protection of marriage and family life in Germany or vocational training. In addition, illness-related dangers, for example if certain illnesses occur due to the planned deportation, lead to the suspension of deportation. Here, psychological and psychosomatic illnesses are often obstacles to deportation. Persons fulfilling these conditions must not be deported.[7]

2.2.4.4. Person enforceably required to leave the country

Section 1 (1) (5) AsylbLG concerns persons who are enforceably required to leave the country. This regulation covers foreigners who have not applied for asylum, whose application has been rejected, as well as persons who have not left the country or have not been deported yet, or who no longer hold a residence permit. Likewise, persons who are in deportation custody are also entitled to benefits under the AsylbLG.[8]

Even persons who illegally stay in Germany may claim these benefits, but for obvious reasons, they rarely realise it.[9]

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[5] Draft of a Law for Management and Limitation of Immigration and for Regulation of the Residence and Integration of Union Citizens and Foreigners [Entwurf eines Gesetzes zur Steuerung und Begrenzung der Zuwanderung und zur Regelung des Aufenthalts und der Integration von Unionsbürgern und Ausländern]. *Deutscher Bundestag Drucksache*, 15/420, 16.01.2003, p. 64.

[6] Draft of a Law to Introduce Accelerated Asylum Procedures (Asylum Package II) [Entwurf eines Gesetzes zur Einführung beschleunigter Asylverfahren (Asylpaket II)]. *Deutscher Bundestag Drucksache*, 18/7538, 16.02.2016, p. 18.

[7] Wahrendorf, “§ 1 AsylbLG”, op. cit., margin number 50–52.

[8] Karla Korff, “§ 1 AsylbLG”. In: Richard Giesen, Ralf Kreikebohm, Christian Rolfs, Peter Udsching, *Beck’scher Online-Kommentar: AsylbLG*. 51st edition. Munich 2018, margin number 18.

[9] Maren Mylius, *Die medizinische Versorgung von Menschen ohne Papiere in Deutschland. Studien zur Praxis in Gesundheitsämtern und Krankenhäusern*. Bielefeld 2016; Wiebke

2.2.5. Follow-up applications

Section (1) (1) (7) AsylbLG covers persons who file a follow-up application claim for a new asylum procedure in Germany, after withdrawal or after an incontestable rejection of their former asylum application (follow-up application). Moreover, foreigners who once apply for asylum in Germany following an unsuccessful asylum procedure in a safe third country (secondary application) fall within the scope of this paragraph. The entitlement to benefits applies only until the decision on the follow-up or subsequent application is incontestable.[10]

2.2.6. Family members

To the spouses, same-sex partners or children of the persons mentioned in section 1 (1) (1) to (5) AsylbLG, section 1 (1) (6) AsylbLG applies. Members of a household community should be treated equally in terms of benefits even if they do not fulfil the conditions stated in section 1 (1) (1) to (5) AsylbLG themselves. Children and adolescents who enter with their parents, a parent or another adult member of the nuclear family are cared for in the family network according to the AsylbLG.

Unaccompanied minor children and adolescents, on the other hand, must be taken into care based on the SGB VIII (Social Security Code No. 8: Child and Youth Welfare Act). Care and accommodation will then take place within the framework of the guidelines for child and youth welfare according to the SGB VIII.

2.2.7. Overview

Table 1 gives a short summary of all the important but still different legal requirements.

The column "Status" refers to the actual legal status that these persons have. The specific permissions that are issued to refugees and asylum seekers are specified in the last column "Title", where the legal basis in the AsylG (German Asylum Act) is shown. The bases for claims, from column one, were examined in more detail above.

Bornschlegl, *Der Zugang von Kindern ohne Papiere zu medizinischer Versorgung in Deutschland. Befunde einer explorativen Studie*. Erlangen 2016; Maren Mylius, Andreas Frewer, "Medizinische Versorgung von Migrantinnen und Migranten ohne legalen Aufenthaltsstatus – Eine Studie zur Rolle der Gesundheitsämter in Deutschland". *Gesundheitswesen* 76 (2014), pp. 440–445.

[10] Franziska Dickten, "§ 71 AufenthG". In: Winfried Kluth, Andreas Heusch, *Beck'scher Online-Kommentar*: *Ausländerrecht, AufenthG*. 20th edition. Munich 2018, margin number 4.

Table 1. Beneficiaries of the AsylbLG

Legal basis section 1 (1)	Status	Title
No. 1 & 6	Asylum application (from safe countries of origin)	Residence authorisation (Permission to remain while the asylum decision is pending), section 55 AsylG
No. 1a & 6	Asylum application	Residence authorisation (Permission to remain while the asylum decision is pending), section 55 AsylG
No. 2 & 6	Airport procedures	Residence authorisation (Permission to remain pending the asylum decision), section 18a (1) sent. 1, 2 AsylG
No. 3a & 6	So-called quota refugees	Residence permit to foreigners from specific states or to certain groups of foreigners, on humanitarian grounds or in order to uphold the political interests
No. 3b & 6	Person required to leave the country (non-enforceable)	Residence permit because of humanitarian or personal reasons, section 25 (4) sen. 1 AufenthG
No. 3c & 6	Person enforceably required to leave the country	Residence permit due to legal or *de facto* reasons, section 25 (5) AufenthG
No. 4 & 6	Suspension of deportation	Temporary toleration of stay, section 60a AufenthG
No. 5 & 6	Person enforceably required to leave the country	Temporary toleration of stay, section 50 AufenthG as well as deportation custody
No. 7	Follow-up applications	Residence authorisation (Permission to remain pending the follow-up application or secondary application decision), section 55 AsylG

Source: own elaboration.

2.3. Healthcare services in special cases

The so-called "*mutatis mutandis* benefits", regulated in section 2 AsylbLG, are made available to the beneficiaries after 18 months. Persons who have completed the waiting period of 18 months are entitled to benefits under SGB XII (Social Security Code No. 12: Social Assistance), which means that they are treated like Germans or foreigners with a residence permit. This also includes standard medical treatment according to the statutory health insurance, cf. section 264 (2) SGB V, without restrictions laid down in sections 4 and 6 AsylbLG. Although the beneficiaries do not become members of the statutory health insurance scheme, benefits are provided according to the principles of health insurance.

This means that they have free choice among doctors and other healthcare providers. However, benefits continue to be financed by the municipalities which are in charge of financing and providing the benefits of the AsylbLG. However, the application *mutatis mutandis* of the general rules of the social assistance scheme is valid only for persons who have not used the duration of their stay in an abusive manner.[11] This is the case, for example, if asylum seekers hide or destroy their passports or go into hiding. When the AsylbLG came into force, the waiting period had been 12 months. In the course of the years, it had been raised to 24, 36 and 48 months; in 2015, it was reduced to 15 months and was raised again to 18 months in 2019. The raising of the waiting period can be seen as a mere political statement and not as a necessary change of the law.

3. Healthcare provisions

The AsylbLG determines the right to healthcare for persons seeking asylum in Germany, their healthcare is regulated by sections 4 and 6 AsylbLG. According to this Act, the right to medical treatment is limited to acute illnesses and conditions of pain. The bureaucratic effort to achieve benefits is high and there is no legal right to treatment of chronic diseases, but this is left to the discretion of the competent authorities. Health check-ups – these are the first examinations in reception facilities – are not regulated by sections 4 and 6 AsylbLG.

Moreover, there is no standardised administrative procedure for access to a health insurance card (eGK). Psychiatric and psychotherapeutic care is provided only to a limited extent. At the same time, the concept of prevention is inherent in the AsylbLG, insofar as the costs for vaccinations and further preventive medical examinations have been borne since 2015. However, the legal provisions do not allow for therapeutic measures related to the prevention of mental illness, although medical science shows that early intervention after (a) potentially traumatic experience(s) can significantly reduce the risk of illness. In addition, various requirements from the statutory health insurance are transferred to the AsylbLG. The associated difficulties for those affected will be explained in more detail later.

3.1. Sickness, pregnancy and childbirth benefits

Section 4 (1) AsylbLG states that the necessary medical treatment must be provided for acute diseases and pain, including pharmaceutical remedies, bandages and other services that are necessary for the cure, improvement

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[11] Irene Vorholz, “Zugang zu Sozialleistungen”. In: Hubert Meyer, Klaus Ritgen, Roland Schäfer (eds.), *Handbuch Flüchtlingsrecht und Integration*. 2nd Edition. Wiesbaden 2018, p. 273.

or alleviation of illnesses or disease outcomes. Section 4 (2) AsylbLG refers to prevention and early diagnosis. However, for the prevention and early detection of diseases, protective vaccinations and medically required preventive medical check-ups are provided. Dental prostheses will only be provided if it cannot be postponed in individual cases for medical reasons.

As we can see, medical care for asylum seekers is limited to the treatment of acute illnesses and pain. There is no legal right to care for chronic diseases. Furthermore, psychiatric and psychotherapeutic treatments are provided only to a very limited extent and are attached to high bureaucratic hurdles such as an official treatment permit, which must be issued by the social welfare authority. Especially PTSD-symptoms such as depression(s), sleep disorders, anxiety and/or flashbacks are hard to diagnose and often misinterpreted by the personnel of these administrative bodies who usually do not have any medical qualifications. Approval depends on the authorities and is handled differently by various authorities in different municipalities. In some cases, there is talk of a better range of benefits than it is given to privately health insured persons. In other cases, there is a very restrictive interpretation of sections 4 and 6 AsylbLG and thus a very small scope of benefits. A connection between symptoms of PTSD and chronic pain has been scientifically proven,[12] which puts those affected in a threatening situation. Treatment is not feasible due to the chronicity of the pain, but treatment due to psychological problems is usually not possible due to limited possibilities of care.

As a rule, only "necessary" treatment will be provided. This means that beneficiaries do not enjoy a right to optimal and best possible medical care.[13] Instead, it is sufficient to take the necessary measures that are sufficient to treat pain or acute disease, disregarding a sustainable, long-lasting treatment success. An obligation to pay benefits in the case of long-term treatment shall be avoided.[14]

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[12] Friedrich Riffer, "Schmerz im Kontext psychiatrischer Versorgung". In: Elmar Kaiser, Friedrich Riffer, Lore Streibl, Manuel Sprung (eds.), *Das Fremde: Flucht – Trauma – Resilienz. Aktuelle traumaspezifische Konzepte in der Psychosomatik*. Berlin 2018, p. 135; Alexandra Liedl, Christine Knaevelsrud, "Chronic pain and PTSD: The Perpetual Avoidance Model and its treatment implications". In: *Torture: Quarterly Journal on Rehabilitation of Torture Victims and Prevention of Torture* 2 (2008), pp. 69–76; Gordon J.G. Asmundson, Michael J. Coons, Steven Taylor, Joel Katz, "PTSD and the experience of pain: research and clinical implications of shared vulnerability and mutual maintenance models". *Canadian Journal of Psychiatry* 47 (2002), pp. 930–937; Timothy J. Sharp, Allison G. Harvey, "Chronic pain and posttraumatic stress disorder: Mutual maintenance?" *Clinical Psychology Review* 21 (2001), pp. 857–877.

[13] Karla Korff, "§ 4 AsylbLG". In: Giesen, Kreikebohm, Rolfs, Udsching, *Beck'scher Online-Kommentar*: *AsylbLG*, op. cit., margin number 13; LSG Baden-Württemberg: Beschl. v. 11.1.2007 – L 7 AY 6025/06 PKH-B, Juris, margin number 55.

[14] OVG Mecklenburg-Vorpommern, Beschl. v. 28.1.2004 – 1 O 5/04, Juris; VG Gera: Urt. v. 7.8.2003 – 6 K 1849/01.GE, Juris.

In addition, interpreting the notion of "necessity" depends on the strength or intensity of individual pain. However, the prerequisite must not be interpreted too narrowly, for example by the adjective "mandatory", as this was not intended by the legislator.[15]

3.2. Section 6 AsylbLG

There is a so-called "catch all" regulation in section 6 AsylbLG, which is simultaneously an "opening clause" for individual cases; it is of utmost importance for the access to mental healthcare for refugees and asylum seekers.

3.2.1. Section 6 (1) AsylbLG

The discretion rule in section 6 (1) AsylbLG is necessary because the benefits in the AsylbLG are limited and refer to a "typical case". Since supplementary benefits such as social assistance are generally not awarded to asylum seekers, it is necessary that in certain cases more extensive benefits can or even must be provided to a limited extent. This is indispensable to guarantee the minimum of subsistence that is in line with human dignity.

The opening clause already opens the possibility for the competent service authorities to consider special medical needs of persons in need of protection – for example with regard to the provision of psychotherapeutic treatment services. The margin of discretion presupposes that the benefit is essential to safeguard the individual's health in the sense of the Reception Directive 2013/33/EU or to cover the needs of children. Besides, it has to cover those needs that are not comprised by the right to healthcare according to section 4 AsylbLG, which is the case especially with chronic illnesses and psychological needs as well as interpreting costs that occur in the context of psychotherapy and other treatments.[16] Therefore, section 6 (1) AsylbLG is the most important norm for the approval of psychotherapeutic services for asylum seekers. A reduction of the discretion under section 6 (1) AsylbLG can also be assumed for particularly vulnerable groups to whom Directive 2013/33/EU grants mandatory entitlement to access to healthcare, which exceeds the scope of benefits under section 4 (1) AsylbLG.

3.2.2. Section 6 (2) AsylbLG

Section 6 (2) AsylbLG contains a privilege for holders of a residence permit in the case of mass-influx. Therefore, unaccompanied minors or persons who have suffered

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[15] VG Osnabrück, Beschl. v. 22.11.1999 – 6 B 61/99, IBIS, p. 120.

[16] Karla Korff, "§ 6 AsylbLG". In: Giesen, Kreikebohm, Rolfs, Udsching, *Beck'scher Online-Kommentar. AsylbLG*, op. cit., margin number 7–9.

torture, rape or other serious forms of psychological, physical or sexual violence are entitled to benefits under this provision; cf. also Article 13 (4) of the Mass Influx Directive. Their right to healthcare includes necessary medical and other assistance, and this norm aims at the medical treatment of physical and psychological long-term consequences which do not express themselves as an acute illness or acute state of pain and would not be covered by section 4 (1) AsylbLG.

However, the provision of section 6 (2) AsylbLG did not have any practical effect so far, since the Mass Influx Directive has not been applied yet, as mentioned above.[17]

4. Specific concepts of the German health insurance

Unlike other countries, Germany has a statutory health insurance and a private health insurance, which both cover 98.2% of the inhabitants.[18] Some legal requirements in the AsylbLG stem from the statutory health insurance SGB V: These are: the notion of disease, the diagnosis requirement and the economic efficiency principle. The transfer of various requirements from the statutory health insurance to the AsylbLG brings up some difficulties for those affected by it.

4.1. Notion of disease

In order to treat and cure a disease, a condition that is defined as such, is indispensable – no disease, no treatment! However, the law does not define exactly what a disease is. It is generally assumed that the notion of illness refers to an abnormal state of body or mind, which deviates from the model of a healthy person, requires medical treatment or leads to incapacity to work.[19] According to section 27 (1) (1) SGB V, there is a right to medical treatment if it is necessary "to detect a disease, to cure it, to prevent its aggravation or to alleviate its symptoms". This may comprise medical treatment, including psychotherapy, hospital treatment and medical rehabilitation services and supplementary services.[20] However, a distinction is made between notions of disease in medicine and in health insurance: whereas the medical term refers to a disease with certain symptoms and causes, a disease in a legal sense refers to the need of treatment and requires

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[17] Ibidem, margin number 18–19.

[18] Rainer Radtke, Statista, *Anzahl der Mitglieder und Versicherten der gesetzlichen und privaten Krankenversicherung in den Jahren 2013 bis 2019* (26.8.2019). Available at: https://de.statista.com/statistik/daten/studie/155823/umfrage/gkv-pkv-mitglieder-und-versicherten-zahl-im-vergleich/ (accessed 06.12.2021).

[19] Ulrich Knispel, "§ 27 SGB V". In: Richard Giesen, Ralf Kreikebohm, Christian Rolfs, Peter Udsching, *Beck'scher Online-Kommentar. Sozialrecht. SGB V.* 52nd Edition. Munich 2019, margin number 5.

[20] LSG Niedersachsen-Bremen, Beschl. v. 10.7.2017 – L 16 KR 13/17, Juris, margin number 23.

a considerable deviation from an ideal state, i.e. a healthy person who is able to exercise normal physical and psychological functions. This is why “minor disorders which do not result in significant functional impairments” are not sufficient. This also means that minor abnormalities that allow for a satisfactory functioning of the body and mind do not constitute a disease requiring treatment.[21] For preventive treatment, this definition is disadvantageous, particularly because no treatment can be offered as long as a disease is not asserted, while at the same time the purpose of early intervention is to prevent the development of diseases. Beneficiaries of the AsylbLG are subject to this definition of SGB V.

4.2. Diagnosis requirement

In general, any treatment requires a diagnosis. This follows from section 295 (1) (1) (1) SGB V, which refers to the obligation to provide at least one diagnosis according to the International Classification of Diseases (ICD). As a consequence, medical treatment can only be provided if at least one diagnosis has been determined based on the ICD. This includes all known illnesses, both somatic and psychological forms, and refers to all services provided, which include all medical measures that are relevant for the reimbursement of costs by the health insurance and may be subject to an audit of billing accuracy, cost-effectiveness and quality.[22]

Similarly to the problem concerning the notion of disease, the requirement of a diagnosis is disadvantageous: Without a manifest diagnosis, no treatment can be initiated, which in turn presupposes the existence of a disease. In the case of PTSD, the ICD-10 definition is problematic due to the included different symptoms. They can vary from sleep disorders, anxiety, flashbacks to depressive behaviour or apathy. But only in combination the individual symptoms do they evolve into PTSD. Thus, as far as prevention of a disease is concerned, the provisions of SGB V for the beneficiaries of the AsylbLG are inadequate. They hinder preventive services in the case of suspected mental problems and lead to a long period between detecting early signs of a potential disease, diagnosis and the following treatment.

4.3. Economic efficiency principle

According to section 12 (1) SGB V, the benefits of the statutory health insurance must be sufficient, appropriate and cost-effective; they must not exceed what is necessary. Benefits that are not necessary or not cost-effective cannot

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[21] Ibidem, margin number 24.

[22] Uwe Schneider, “§ 295 SGB V”. In: Regine Wagner, Stefan Knittel, *Krauskopf, Soziale Krankenversicherung Pflegeversicherung*. 103rd Edition. Munich 2017, margin number 7.

be claimed by insured persons, may not be provided by the service providers and may not be reimbursed by the health insurance funds.[23]

Nevertheless, the principle of cost-effectiveness has to be applied to beneficiaries who are covered by sections 1 (1) and (3) AsylbLG as well.[24] In contrast, German courts do not consider the principle of cost-effectiveness to be relevant in the context of the AsylbLG. "On the other hand, the 'principle of cost-effectiveness' does not apply. The central cost argument [...], which is quite understandable, is completely irrelevant in the context of the examination of [...]", sections 4, 6 AsylbLG.[25] Hence, in this particular case, the desired treatment – a kidney transplant – was not granted because its costs were not considered as relevant. Instead, the plaintiff received a long-term kidney dialysis at higher costs, because according to section 4 AsylbLG, beneficiaries are entitled to the "necessary" treatment only, irrespective of its cost-effectiveness. This appears even more ironic, considering the financing of the AsylbLG and SGB V: While health insurance is financed from contributions, AsylbLG benefits are free of charge. Moreover, the competent authorities bear the costs and reimburse them. Hence, only members of the statutory health insurance schemes are entitled to sufficient, appropriate and cost-effective treatment, whilst beneficiaries entitled to the AsylbLG would receive worse treatment, although at a higher price.

On the contrary, this means that for insured persons entitled to benefits, the principle of economic efficiency must be applied strictly and there is no entitlement to a more expensive, albeit more efficient, benefit, provided that the economic benefit is sufficient and expedient. For beneficiaries of the AsylbLG, however, the benefit may be less efficient and more expensive at the same time. Certainly, the benefits of the insured are financed by the insurance contributions, and those of the AsylbLG beneficiaries are reimbursed by the responsible institutions. However, this cannot be summarily conclusive. Since the prerequisites of SGB V equally apply in the other areas of healthcare, the cost efficiency principle must be observed consistently. In exceptional cases, this leads to the granting of benefits apart from the listed facts, or the cost efficiency principle cannot be applied to the AsylbLG. This result is proven by historical interpretations. After all, in 1993, with the introduction of the AsylbLG, the legislator wanted to achieve a significant reduction in costs and a restriction of health services for asylum seekers: "Savings of up to DM 2 billion [German Mark, former currency of Germany] a year are expected for Länder [German federal states] and municipalities".[26] A non-application of the principle of cost-effectiveness is, therefore, contrary to the norm and hence not tolerable.

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[23] LSG Niedersachsen-Bremen, op. cit., margin number 23.

[24] Korff, "§ 4 AsylbLG", op. cit., margin number 12.

[25] OVG Mecklenburg-Vorpommern, op. cit., margin number 22.

[26] Draft of a Law to Reorganize Benefits for Asylum Seekers, op. cit., pp. 1, 6.

5. European Union

The Treaty on the European Union (TEU) and the Treaty on the Functioning of the European Union (TFEU) form the legal basis of the European Union. Besides, the Charter of Fundamental Rights of the EU and numerous regulations, decisions and directives are central to the functioning of the EU and the Member States. Regulations and decisions are directly applicable in all the EU Member States from the day they come into force. Directives, on the other hand, have to be transformed into national law by the Member States within a period specified in the directive. In the following sections, individual extracts from the Treaty on the Functioning of the European Union, the Charter of Fundamental Rights of the European Union (CFR) and the Reception Directive 2013/33/EU will be reviewed for their significance with regard to access to healthcare for refugees and asylum seekers within the EU and Germany.

5.1. TFEU

The Treaty on the Functioning of the European Union governs the functioning of the Union and defines the fields, limits and procedures for the exercise of its competences (Article 1 (1) TFEU). Together with the Treaty on European Union, both Treaties of the same legal status constitute the Treaties on which the Union is founded (Article 1 (2) TFEU).

"The Union shall develop a common immigration policy aimed at ensuring, at all stages, the efficient management of migration flows, fair treatment of third-country nationals residing legally in a Member State, and the prevention of, and enhanced measures to combat, illegal immigration and trafficking in human beings" (Article 79 (1) TFEU). Article 79 TFEU has greater relevance for the questions to be dealt with. It defines four competences for the Union in relation to a common immigration policy as a guideline. The different points are not to be understood separately and uniquely but form a cycle which includes both immigration and emigration actions (deportation and return).

1. Common immigration policy: a common immigration policy is to be developed for this purpose.
2. Migration management: the common immigration policy should aim at ensuring the effective management of migration flows at all stages.
3. Appropriate treatment: third-country nationals (including stateless persons; Article 67 (2) TFEU) who are legally resident in a Member State must be treated appropriately. The fundamental rights standards of the CFR must be observed.

4. Combating illegality: illegal immigration and human trafficking must be prevented and combated.[27] Regulations on combating illegality must above all comply with the limits of the Geneva Convention and the ECHR (European Convention on Human Rights); especially Article 3 and Article 8 ECHR.[28]

In short, it is a matter of effectively managing so-called “migration flows” through a common immigration policy, of adequately treating third-country nationals who reside legally, and of preventing and combating illegal immigration and trafficking human beings.

Particularly, the issue of adequate treatment should be considered more closely in this context, as the assessment of adequacy is subjective. In the English version of the legal text, a “fair treatment” of third-country nationals residing legally in the Member States is required. The German translation of “angemessen” can be understood as “proportionate” or “commensurate”, while “fair treatment” would be translated as “equitable treatment”.

Although it is argued that this “Union migration(-control) law” cannot be justified from the perspective of the migrants concerned as the “sole starting point”, it must respect the (human) rights of the migrants.[29] These objectives are binding for the Union legislation, even if the scope for implementing the Treaty objectives is limited.[30]

Both the Bundestag and the Bundesrat have commissioned the European Union to implement the four objectives set out in Article 79 TFEU. This also makes it possible for EU secondary law to have a greater impact on German foreigners’ internal law.[31]

5.2. CFR

The Charter of Fundamental Rights of the European Union was signed in 2000 and has an impact on the work of the EU. Legislative proposals are checked for compatibility with the Charter, and the Charter is referred to before the European Court of Justice (ECJ). Citizens of the Union can seek legal redress in the case of violation of their fundamental rights. This was made possible

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[27] Peter-Christian Müller-Graff, “Article 79 AEUV”. In: Matthias Pechstein, Carsten Nowak, Ulrich Häde, *Pechstein/Nowak/Häde, Frankfurter Kommentar EUV/GRC/AEUV*. Tübingen 2017, margin number 8.

[28] Matthias Rossi, “Article 79 AEUV”. In: Christian Calliess, Matthias Ruffert, *Calliess/Ruffert, EUV/AEUV*. Munich 2016, margin number 22.

[29] Daniel Thym, “Article 79 AEUV”. In: Martin Nettesheim, *Grabitz/Hilf/Nettesheim Das Recht der Europäischen Union*. 67th Edition. Munich 2019, mag 17.

[30] Ibidem, margin number 14.

[31] Jan Bergmann, “Abschied vom deutschen Ausländerrecht? Europarechtliche Provokationen”. *Zeitschrift für Ausländerrecht und Ausländerpolitik* 33 (2013), p. 323.

by the legally binding nature of the Charter of Fundamental Rights, which came into force in 2009, because of the Lisbon Treaty.[32]

The right to physical and mental integrity is enshrined in Article 3 (1) of the CFR. Article 34 (1) CFR establishes access to social security benefits and services in the event of sickness. Article 35 CFR deepens the right of access to healthcare. This was the aim of the first EU health strategy,[33] which was intended to ensure solidarity and equality in health policy within the EU, and the current third strategy, "Health for Growth".[34] Article 35 CFR does not only provide for the treatment of diseases, but also for preventive services.[35] In addition, special attention is paid to older people, young people and adults at work as well as people with disabilities; cf. Articles 25, 32, 31 and 26 CFR. Discrimination in all respects is prohibited by Article 21. No differentiation is made between physical and mental health.[36] Article 35 CFR, therefore, contains a purely subjective right to health in the sense of healthcare and prevention for every human,[37] taking into account the other relevant norms. The CFR, therefore, does not contain an independent right to health.[38] The CFR is not only effective for Union citizens, but for all persons living in the territory. The treatment of refugees must therefore comply in each Member State with the requirements of the Charter, the Geneva Convention and the ECHR.

5.3. Reception Conditions Directive

The so-called Reception Conditions Directive 2013/33/EU lays down certain minimum reception standards for access to healthcare for asylum seekers in the Member States. According to Article 2 (b) Directive 2013/33/EU,

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[32] *The protection of fundamental rights in the EU*. European Parliament. Available at: https://www.europarl.europa.eu/factsheets/en/sheet/146/the-protection-of-fundamental-rights-in-the-eu (accessed 06.12.2021).

[33] Together for Health. A Strategic Approach for the EU, 2008–2013. European Commission, COM(2007) 630 final. Available at: https://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf (accessed 06.12.2021).

[34] Proposal for a regulation of the European Parliament and of the Council on establishing a Health for Growth Programme, the third multi-annual programme of EU action in the field of health for the period 2014–2020. European Commission, COM(2011) 709 final. Available at: https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX%3A52011PC0709 (accessed 06.12.2021).

[35] Tamara K. Hervey, "We don't see a connection. the 'right to health' in the EU Charter and European Social Charter". In: Gráinne de Búrca, Bruno de Witte (eds.), *Social Rights in Europe*. New York 2005, p. 315.

[36] Beate Rudolf, "Article 35 EUGRCh". In: Jürgen Meyer, *Charta der Grundrechte der Europäischen Union*. 4th Edition. Baden-Baden 2014, margin number 10.

[37] Rudolf, "Article 35 EUGRCh", op. cit., margin number 13.

[38] Hervey, "We don't see", op. cit., p. 314.

the Directive applies to persons who have applied for international protection within the meaning of Article 2 (h) of Directive 2011/95/EU, and to their family members according to Article 2 (c) Directive 2013/33/EU, and in relation to whom a final decision has not as yet been taken, as well as to unaccompanied minors (Article 2 (e) Directive 2013/33/EU). The Directive therefore only concerns those entitled to benefits under the AsylbLG which fulfil the conditions of section 1 (1) (1), (1a), (2), (7) and possibly (6) AsylbLG, i.e. persons who have proof of arrival or a residence authorisation (permission to remain pending the asylum decision) for the duration of the proceedings.

The Reception Conditions Directive (previously: Directive 2003/9/EC) provides for the protection of physical and mental health (Article 17 (2) Directive 2013/33/EU), emergency care for serious mental disorders (Article 19 (1) Directive 2013/33/EU) and appropriate psychological care for persons with special needs (Article 19 (2) Directive 2013/33/EU). In addition, persons with mental illness, victims of trafficking and persons who have suffered torture, rape or other serious forms of psychological, physical or sexual violence are classified as persons in need of protection under Article 21 Directive 2013/33/EU. In particular, they shall be provided with psychological care, treatment and qualified counselling; cf. Article 22 (4), Article 25 (1) Directive 2013/33/EU. Furthermore, Article 13 Directive 2013/33/EU states that the EU Member States may require health checks for applicants for international protection on grounds of public health security. However, there is no obligation to carry out such screenings.

In the eyes of the European Commission, the Directive was not sufficiently implemented in Germany, which is why the European Commission initiated an infringement procedure. The Federal Government denied[39] this and stated that it fulfils the requirements of the Directive through the discretionary clause in section 6 (1) AsylbLG.[40] In 2019, the European Commission followed the German standpoint and closed two ongoing proceedings against Germany[41] with no further explanation, as the Federal Government continued to insist that "the medical care provided by the Länder, the national asylum procedure law

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[39] State of Development and Implementation of the Inclusion Requirement in the Federal Republic of Germany [Entwicklungsstand und Umsetzung des Inklusionsgebotes in der Bundesrepublik Deutschland]. *Deutscher Bundestag Drucksache*, 18/6533, 29.10.2015, p. 106.

[40] Improvements in Health and Psychosocial Care for Refugees to Implement the EU Reception Directive [Verbesserungen der gesundheitlichen und psychosozialen Versorgung von Geflüchteten zur Umsetzung der EU-Aufnahmerichtlinie]. *Deutscher Bundestag Drucksache,* 18/9009, 04.07.2016, p. 10.

[41] European Commission, *Vertragsverletzungsverfahren im Oktober: Entscheidungen zu Deutschland* (10/10/2019). Available at: https://ec.europa.eu/commission/presscorner/detail/de/inf_20_1687 (accessed 06.12.2021).

and the practice of the Federal Office of Migration and Refugees [BAMF] [...] would be in accordance with the requirements of European law".[42]

On a positive note regarding the Reception Conditions Directive, the provisions of Articles 20 and 17 of the previous Directive 2003/9/EC in conjunction with section 6 AsylbLG mean that the discretion in the provision of interpreting services is reduced to zero.[43] Also, a reduction of the discretion under section 6 (1) AsylbLG can be assumed for particularly vulnerable groups who are granted entitlement to access to healthcare beyond the scope of benefits under section 4 (1) AsylbLG by the Directive 2013/33/EU.[44]

6. Findings

At the beginning, it was shown how different groups are treated equally irrespective of the different situations they are confronted with. Likewise, the reasons which make these persons leave their (home) countries are mentioned; however, they are ignored by the legislation. Even children may fall within the scope of the AsylbLG if they are accompanied by their parents or other relatives and therefore have restricted access to healthcare. In the light of the UN Convention on the Rights of Children, this is questionable for many reasons.[45] It appears that the AsylbLG is a melting pot for all persons seeking protection, whom the government does not want to include in the regular social assistance scheme. In order to achieve this goal, measures such as an extension of the waiting period, which in its original form of 15 months had already been strongly criticised by the associations of those affected, have not been shied away from.

Also, sections 4 and 6 AsylbLG are very restrictive, as has been shown. They were severely limited based on the assumption that the length of stay would

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[42] Psychosocial Care and Treatment of Traumatized Refugees [Psychosoziale Betreuung und Behandlung von traumatisierten Geflüchteten]. *Deutscher Bundestag Drucksache,* 19/11666. 15.07.2019, p. 4.

[43] Bundesministerium für Arbeit und Soziales: Dolmetscher – Ermessen (21.2.2011). Available at: https://www.lpk-rlp.de/fileadmin/user_upload/Anlage_zum_Schreiben_vom_25.01.2012.pdf (accessed 06.12.2021).

[44] On the Situation of Hearing Impaired People in Germany [Zur Situation von hörbeeinträchtigten Menschen in Deutschland]. *Deutscher Bundestag Drucksache,* 19/1620, 12.04.2018, p. 16.

[45] Gabriele Kokott-Weidenfeld, Kurt-Peter Merk, "Handlungsfeld der Sozialen Arbeit: Geflohene Kinder und Familien". In: Birgit Wartenpfuhl (ed.), *Soziale Arbeit und Migration. Konzepte und Lösungen im Vergleich*. Wiesbaden 2019, p. 75; Thomas Meysen, Susanne Achterfeld, "Geflüchtete Kinder und Jugendliche im Spannungsfeld von Kinder- und Jugendhilfe-, Familien- und Ausländerrecht". In: Roman Lehner, Friederike Wapler (eds.), *Die herausgeforderte Rechtsordnung. Aktuelle Probleme der Flüchtlingspolitik*. Berlin 2018, pp. 326–327.

be short, and long-term treatment would therefore not be appropriate. Even treatments that are not clearly indicated cannot be granted from this point of view. Beyond that, the fact that the Mass Influx Directive is currently not applicable, is an unconscionable act by the EU Member States. The approval of psychotherapy is extremely complicated and bureaucratic, which is an insurmountable hurdle for many of those affected. Especially when one considers the situation that leads to the fact that a therapy seems necessary. Legislation and politics have no interest in the concerns of the affected persons; rather, they are relying on deterrence and, in this way, aggravate the problem.

There is a wide gap between the services of SGB V and the services of the AsylbLG for healthcare. Nevertheless, the provisions of SGB V are applied without explanation to the AsylbLG. The regulations are already problematic for the regularly insured persons. It seems questionable to apply them to a group affected by special medical circumstances. This is shown, among other things, by the diagnosis of PTSD and other mental illnesses. Preventive measures for mental illnesses are provided only to a very limited extent for the insured, and not at all for the refugees of the AsylbLG – at least not by the state.

As AsylbLG is seen as an independent benefit law, it is not understandable why the conditions of SGB V are applicable. Rather, it would make sense either to develop specific conditions in accordance with the beneficiaries or, even better, to abolish the benefits of sections 4 and 6 AsylbLG from the AsylbLG and to apply the benefits of SGB V throughout.

The direct impact of the TFEU on the healthcare for AsylbLG beneficiaries is small since the TFEU establishes abstract rights and no individual claims. Nevertheless, the proportionate/fair treatment of third-country nationals in the Member States, which includes AsylbLG beneficiaries, is particularly important. There is no answer on how "fair" access to healthcare is for beneficiaries of the AsylbLG.[46] In any way, the fundamental rights standards of the CFR must be observed. Even in the CFR, there is no starting point for an independent (human) right to health. Due to the diversity of the individual Member States, it seems impossible to guarantee certain rights unconditionally. Even directives that are more application-oriented cannot be convincing. The content of the Reception Conditions Directive is very promising but, unfortunately, it is said to be adequately implemented in individual countries, such as Germany, but the changes that were made in the AsylbLG after 2016 were only restrictive ones, so that the implementation of substantive regulations is rather unlikely. This is why the effect becomes ineffective. Many of the European Union requirements

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[46] Gisbert Brinkmann, *EU-Migrationsrecht für Drittstaatsangehörige* (27.01.2018). Available at: https://www.akademie-rs.de/fileadmin/user_upload/download_archive/migration/20180126 _brinkmann_drittstaatsangehoerige.pdf (accessed 06.12.2021).

are promising and can, to a large extent, contribute to better provision for refugees, but there are far-reaching shortcomings to be found in the area of access to the health system.

7. Conclusion

Access to the health system in Germany is inadequate, must be granted in full and must not be prevented. Even in the light of the Union law, equal conditions must prevail for refugees and natives. Considering the human dignity and the EU right to health, these people must not be left alone to deal with the experiences without protection but need adequate offers such as adequate support to strengthen self-help capabilities. Psychological-psychotherapeutic care of the refugees in Germany, especially in the first 18 months of uncertain residence status, is inhumane and could be seen as illegal. Although other European Member States allow even lesser access to the health system, this cannot be the yardstick. Especially not for a country like Germany, which sees itself as a role model within the EU and worldwide. Expressly not if we consider that our actions can fall back on us. The consequences of neglected support, both curative and preventive, include incapacity for work, addiction, delinquent behaviour and revictimisation, as well as suicidal behaviour and chronification of psychological and psychosomatic illnesses. It must also be borne in mind that people would not have to suffer from psychological issues if they were offered the lowest level of support early on, which is why an early intervention strategy for mental problems would reduce costs and bureaucratic procedures. The benefits to the affected persons, civil society, healthcare system and politics are diverse. Legislation and politics at the EU and national level show no interest in the concerns of asylum seekers and refugees; rather they are relying on deterrence and, in this way, aggravate the problem. This leads to persons being exposed to an increased risk of disease without protection, which in turn has a negative effect on the living conditions of all persons living in the receiving country and in the country of origin. If the required cycle were to be adhered to, everyone could live a healthy life both in Germany and in other Member States through permanent access to the healthcare system and make a positive contribution to the social and community life, as well as be prepared for a possible return to their countries of origin, and thus contribute to a stable development there.

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Katarzyna Ewa Król

Navigating the void: A qualitative study of patients with rare inborn errors of metabolism perception of healthcare regulations

1. Introduction

Increased global attention on rare diseases, followed by a number of regulatory and research initiatives aiming at facilitating patients' access to treatment, did not lead to the creation of internationally accepted definition of "rare disease", thus creating significant legal differences across countries.[1] Therefore, it is crucial to note that the following analysis applies the definition of "rare disease" the way it is used in the European Union. According to the European Organisation for Rare Diseases (henceforth: EURORDIS), "a rare disease is a disease that occurs infrequently or rarely in the general population".[2] In order to be defined as such in Europe, its prevalence cannot exceed more than 1 in 2,000 citizens.[3] Rare inborn errors of metabolism (henceforth: IEM) constitute a non-negligible group of rare disorders. As such, they are often severe, chronic, disabling and possibly lethal conditions which require highly specialised and coordinated care throughout life. Treatment is clinically challenging and requires patients (often children) and their family members to follow a dietary regimen for the rest of their lives.[4] Even following the recommendations does not prevent patients from hospitalisation – they are prone to episodes biomedically known as a metabolic crisis, which can lead to a range of consequences – from lack of energy and difficulties

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[1] Trevor Richter, Sandra Nestler-Parr, Robert Babela, Zeba M. Khan, Theresa Tesoro, Elizabeth Molsen and Dyfrig A. Hughes, "Rare disease terminology and definitions – A systematic global review: Report of the ISPOR Rare Disease Special Interest Group". *Value in Health* 18 (2015), pp. 906–914.

[2] Eurordis, *Understanding This Public Health Priority*. Paris 2005, pp. 1–14. Available at: https://www.eurordis.org/sites/default/files/publications/princeps_document-EN.pdf (accessed 27.05.2021).

[3] Ibidem, p. 6.

[4] Ewa Emczyńska-Seliga, "Terapia dietetyczna wybranych wrodzonych wad metabolizmu – część 1". *Polish Journal of Nutrition* 2 (2016), pp. 24–31.

with eating to permanent neurological damage.[5] It is important to underline that, although some of the observations and conclusions presented in this chapter could apply equally to other groups of patients with rare diseases, others will significantly differ. The situation will be specifically different for patients for whom medical therapy is available (which applies to only around 3% of diseases). This chapter, however, focuses exclusively on the discourses expressed by the parents of children for whom treatment protocols are limited to following a strict diet and usage of medical foods.

IEMs are caused by mutations in gene coding for enzymes and other proteins involved in cell metabolism and in most cases are diagnosed in childhood; thus parents are the primary caregivers responsible for navigating the healthcare system. In this chapter, I analyse the data gathered from interviews conducted solely with the parents of children afflicted by IEM, not with the patients themselves. The distinction is important, since the previous scholarship about rare disorders in France has shown significant differences in the judgment of expectations towards healthcare systems and treatment issues between parents and patients. Similarly, both groups have different priorities – parents' associations tend to support medical research, while patients' associations prioritise healthcare improvement.[6]

I look at the parental discourses in relation to: healthcare regulations, the ways of parental manoeuvring in the unregulated environment, and statements and claims emerging from these encounters from people who will potentially acquire new rights. I want to see if and how debates about possible changes in law concerning IEM patients play out in individual lives – namely, I want to observe the variety of ways in which rights (or lack of them) become present in the lives of the group under study. This paper takes a qualitative approach and looks at the parental discourses in relation to: healthcare regulations, the ways of parental manoeuvring in the unregulated environment, and statements and claims emerging from these encounters. It also shows how legal factors determine parental strategies in advocating for children's best interests. I focus specifically on the situation of the parents of IEM patients in three aspects – their "legal consciousness", struggles with obtaining a certificate of disability, and process of transitioning from paediatric to adult healthcare.

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[5] Charlotte Bieneck Haglind, *Energy Metabolism and Clinical Symptoms in Beta-Oxidation Defects, Especially Long-Chain 3-Hydroxyacyl-Coenzyme A Dehydrogenase Deficiency*. University dissertation, Stockholm 2016.

[6] Caroline Huyard, "How did uncommon disorders become 'rare diseases'? History of a boundary object". *Sociology of Health & Illness* 31 (2009), pp. 463–477.

2. Theoretical approach

A rich body of research on knowledge production in health and illness showed how biomedical knowledge is embedded in social, cultural and political contexts.[7] In my analysis, I look at healthcare as a medical space where processes of social exclusion and inclusion can be shaped. Here, I refer to Foucault's spatial understanding of modern medicine, recognising twofold forms of medical dominance – territorialising individual bodies through diagnostic gaze, as well as public spaces through health surveillance.[8] I suggest, however, to look beyond the usual social diversity determinants framed as ethnicity, religion, gender and sexual orientation, and extend it by adding the dimension of biosociality and look at the "novel populations" based on particular biosocialities as suggested by sociologist Carlos Novas.[9] In order to do so, I bring together two academic literatures – namely the sociology of law and social and cultural studies of science, technology and medicine in order to design the analytic toolkit out of this assemblage. I borrow the understanding of "assemblages" from Aihwa Ong and Stephen Collier, who use this term to describe how global forms get defined in specific situations as new material, collective and discursive relationships and to analyse the "domains in which the forms and values of individual and collective existence are problematised or at stake, in the sense that they are subject to technological, political and ethical reflection and intervention".[10] Theoretically, this chapter draws on French pragmatic sociology which integrates American pragmatist tradition and phenomenology in order to study "actors in indeterminate social situations and take(s) the reflexivity and capacities of people's common sense seriously".[11]

The idea that law is one of the categories shaping everyday life was a central object of theoretical and substantive concern since the beginnings of sociology – to name only foundational works by Émile Durkheim and Max Weber.[12] The approach of observing mutually constitutive relationships between law and the social context it is embedded in has been continued by scholars like

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[7] Margaret M. Lock, Vinh-Kim Nguyen, *An Anthropology of Biomedicine*. Hoboken 2018.

[8] Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*. New York 1973.

[9] Carlos Novas, "Patient activism and biopolitics: thinking through rare diseases and orphan drugs". In: Vernon W. Cisney, Nicolae Morar (eds.), *Biopower. Foucault and Beyond*. Chicago 2015, pp. 183–198.

[10] Aihwa Ong, Stephen Collier, *Global Assemblages Technology, Politics, and Ethics as Anthropological Problems*. Malden 2007, p. 4.

[11] Bruno Frère, Daniel Jaster, "French sociological pragmatism: inheritor and innovator in the American pragmatic and sociological phenomenological traditions". *Journal of Classical Sociology* 19 (2018), pp. 138–160.

[12] Alan Hunt, *The Sociological Movement in Law*. London 1978.

Barbara Yngvesson to show how legal order and sociocultural order "mutually shape" one another.[13] One of the theoretical inspirations for this chapter came from the work of David M. Engel and Frank W. Munger, who analyse the intersection of legal regulation and individual biographies of people with disabilities in the United States.[14] First, they point to the importance of studying life stories when conducting research on rights. They offer ethnographically informed analysis of relevance and irrelevance of laws based on biographical interviews. Thus, they were able to observe the effects of new laws targeting people with disabilities over the course of their lifetimes and see to what extent legal changes and innovations make an impact on particular life stages. Second, they complicate our understanding of the way in which we look at the relationship between individuals and law – traditionally scholarship about legal implementation tended to have an adverbial approach in which individuals can either invoke the new law or not. They show that laws become significant in people's lives on many other levels and the "use" of them is not limited to only explicit legal invocation. This perspective proves to be especially interesting to me, as my research concerns people in the "pre-enactment stage" – thus it allows me to analyse possible narratives about hopes, or lack of them, placed in the National Plan for Rare Diseases (further: NPRD). It also shows that there are a number of gaps in our knowledge concerning law and society scholarship that would benefit from further research if, for example, the enactment of the NPRD took place.[15]

The second scholarship I intend to use derives from studies of science, technology, and medicine, and positions the biopolitical paradigm at its centre. The biopolitical paradigm, according to sociologist Steven Epstein, is conceptualised as "frameworks of ideas, standards, formal procedures and unarticulated understandings that specify how concerns about health, medicine and the body are made the simultaneous focus of biomedicine and state policy".[16] By observing biomedical research and state policies in the United States, Epstein analyses not only how biomedicine gets politicised, but, more importantly, how governing gets "biomedicalised".[17] Adele E. Clark defined the term "medicalisation" as:

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[13] Barbara Yngvesson, "Making law at the doorway: The clerk, the court, and the construction of community in a New England town". *Law and Society Review* 22 (1988), pp. 409–448.

[14] David M. Engel, Frank W. Munger, *Rights of Inclusion: Law and Identity in the Life Stories of Americans with Disabilities*. Chicago 2003.

[15] Which indeed happened in August 2021, however changes caused by its implementation are beyond the scope of this study.

[16] Steven Epstein, *Inclusion of the Politics of Difference in Medical Research*. La Vergne 2017, p. 17.

[17] Ibidem, p. 18.

> largely technoscientific changes in biomedicine [which] are transforming the twenty-first century. Biomedicalisation is our term for the increasingly complex, multisited, multidirectional processes of medicalisation that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine.[18]

For Epstein, "medical research becomes reconceived as a domain in which a host of political problems can get worked out the nature of social justice, the limits and possibilities of citizenship, and the meanings of equality and difference at the biological as well as social levels".[19]

The new age of biomedicine, biotechnology and genomics created the new type of citizenship – "biological citizenship".[20] Nikolas Rose and Carlos Novas pointed out that biological citizenship serves both as an individualising and collectivising power. On individual level, it refers to the extent of how "individuals shape their relations with themselves in terms of a knowledge of their somatic individuality".[21] On collective level, it refers to the notion of "biosociality" introduced by Paul Rabinow[22] to show how "new ethical technologies are being assembled around the proliferating categories of corporeal vulnerability, somatic suffering, and genetic risk and susceptibility".[23] Since then, the term "biosociality" is used to analyse patient activism built around "new genetics".[24] I suggest using the term of "biological citizenship", first introduced by Adriana Petryna, to describe "a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it"[25] in the aftermath of the Chernobyl disaster. Since her book, other scholars took on the term to explore how biological knowledge is increasingly connected to citizenship projects. I apply it to trace IEM patients' claims for social welfare based on medical, scientific and legal criteria.

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[18] Adele E. Clarke, Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, "Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine". In: Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, Janet K. Shim (eds.), *Biomedicalization. Technoscience, Health, and Illness in the U.S.* Durham 2010, p. 47.

[19] Epstein, *Inclusion*..., op. cit., p. 18.

[20] Nikolas Rose, Carlos Novas, "Biological citizenship". In: Aihwa Ong, Stephen J. Collier (eds.), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Malden 2010, pp. 439–463.

[21] Ibidem, p. 444.

[22] Paul Rabinow, "Artificiality and enlightenment: From sociobiology to biosociality". In: idem, *Essays on the Anthropology of Reason*. Princeton 1996, p. 91–111.

[23] Rose, Novas, "Biological citizenship", op. cit., p. 446.

[24] Rabinow, "Artificiality...," op. cit., p. 99.

[25] Adriana Petryna, *Life Exposed. Biological Citizens after Chernobyl*. Princeton 2002.

A slowly growing social science scholarship on (rare) genetic disorders in Poland covered various aspects of living with such diagnosis, mostly focusing on: relations within the family and parental discourses around ambiguous diagnosis and symptoms in IEM,[26] negotiations about the definition and perception of disability in case of RD patients,[27] medicalised diets as a biomedical tool and its clash with "traditional" parenting discourses,[28] gendered discourses about genetic femininity in Turner syndrome,[29] bioethical challenges and methods of body enhancement in Turner's syndrome.[30] An article by Anna Krawczak, analysing reproductive possibilities and rights of women affected by Turner's syndrome, shows how individual decisions are embedded in entangled networks of cultural, social and legal regulations. It also points to the co-dependency of social and legal frameworks, which this chapter takes as the point of departure.[31]

3. Legal background

In 2009, the Council of the EU issued a "Recommendation on action in the field of rare diseases".[32] It recognised that, although individually each of these diseases does not impact a lot of people, in total they affect 6%–8% of the population during their lifetime, which means that between 27 and 36 million people are conditioned by rare diseases in the EU.[33] The Recommendation stated that:

> rare diseases are a threat to the health of EU citizens insofar as they are life-threatening or chronically debilitating diseases with a low prevalence and a high level

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[26] Anna Chowaniec-Rylke, "Nigdy do końca zdrowi, nigdy dość chorzy. Doświadczenia rodziców dzieci chorych na LCHADD". Magdalena Radkowska-Walkowicz, Maria Reimann (eds.), *Dzieci i zdrowie. Wstęp do childhood studies*. Warsaw 2018, pp. 288–308.

[27] Anna Chowaniec-Rylke, "Posiłek co dwie godziny, czyli o relacjach rodzinnych, zarządzaniu dietą i definicjach niepełnosprawności w przypadku rzadkiej choroby metabolicznej". *Etnografia Polska* 62 (2018), pp. 163–182.

[28] Małgorzata Rajtar, "Normalised eating and dietary guidelines in LCHAD deficiency". *Ethnologia Polona* 40 (2019), pp. 91–108.

[29] Magdalena Radkowska-Walkowicz, "Nikt nie rodzi się kobietą? Zespół Turnera i zwierciadła kobiecości". In: eadem, Ewa Maciejewska-Mroczek, Maria Reimann (eds.), *Zespół Turnera. Głosy i doświadczenia*. Warsaw 2019, pp. 113–140.

[30] Małgorzata Rajtar, "Bioetyka i technologie wzmacniania ludzkiego ciała w kontekście doświadczeń kobiet z zespołem Turnera". In: Radkowska-Walkowicz, Maciejewska-Mroczek, Reimann (eds.), *Zespół Turnera*, op. cit., pp. 171–197.

[31] Anna Krawczak, "Zespół Turnera. Macierzyństwo w planach". In: Radkowska-Walkowicz, Maciejewska-Mroczek, Reimann (eds.), *Zespół Turnera*, op. cit., pp. 79–112.

[32] Council Recommendation of 8 June 2009 on an action in the field of rare diseases. *Official Journal of the European Union*, C 151, 3.07.2009, pp. 7–10.

[33] Ibidem.

> of complexity. Despite their rarity, there are so many different types of rare diseases that millions of people are affected.[34]

In order to respond to that relatively new public healthcare issue, the Council urged Member States to prepare and adopt a plan or strategy for rare diseases by the end of 2013 at the latest. It is vital to note that the EU recommendations regarding the establishment of National Plans for Rare Diseases have been implemented in most EU countries, but not in Poland.

When analysing the normative landscape of these disorders, it is important to remember that the very category of "rare diseases" is a "by-product of the definition of orphan drugs".[35] The term itself appeared in the U.S. in the mid-1970s and was appropriated in the U.S. Orphan Drug Act of 1984, and later in Europe.[36] Importantly, the term "rare disease" does not exist in the current Polish legal order[37] although the Ministry of Health in its documents uses the same definition as adopted under the EU regulations. Thus, the legal situation of people affected by rare diseases is a result of the intersection of the non-existent promised regulations from the NPRD and the existing laws concerning people with disabilities.

In order to meet the EU recommendation, in July 2008 the Ministry of Health established a Task Force for Rare Diseases intended as a consultative and advisory body, with its main task to ensure access to diagnosis, therapy and adequate care for patients with rare diseases. The task force included the state representatives from: the Ministry of Health, the Office for Registration of Medicinal Products, Medical Devices and Biocidal Products, the Chief Pharmaceutical Inspectorate, the Agency for Health Technology Assessment and Tariff System, as well as: three experts representing science and medicine, patients organisation representatives and one ethicist.[38] In 2011 systemic recommendations for the National Plan for Rare Diseases for 2013–2017 were developed as a result of extensive consultations led by the Polish National Forum on the Treatment of Orphan Diseases – ORPHAN. By the end of 2012 the document "National Plan for Rare Diseases – Roadmap" was ready, but not implemented. Since then, the team of the Task Force itself has changed several times, each time coming up with slightly different drafts of the Plan. In 2019 a new team prepared the Plan, which it intended to finish a decade long struggle. In June 2019 the project appeared on the Ministry's website, accompanied by promises of finishing the procedure by the end of the calendar year. As the end of the year

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[34] Ibidem.

[35] Caroline Huyard, "How did...", op. cit., p. 465.

[36] Ibidem.

[37] Maria Libura, Magdalena Władusiuk, Monika Małowicka, Edyta Grabowska, Małgorzata Gałązka-Sobotka, Jerzy Gryglewicz, *Choroby rzadkie w Polsce: stan obecny i perspektywy*. Warsaw 2016.

[38] Ibidem, p. 30.

was inevitably approaching and hopes of seeing the Plan adopted started to fade, the Ministry postponed the deadline until the International Day of Rare Diseases, celebrated on the last day of February. After failing to meet the deadline, in March 2020 yet another expert team was appointed at the Ministry of Health with the aim of preparing specific recommendations for the National Plan for Rare Diseases, with the deadline set for June 2020.[39] By the end of the same month the Representative for NPRD implementation appointed by the Minister of Heath was dismissed, and the office itself was dismantled.[40] I reconstruct this long and repetitive story of the raising expectations and failing patients' hopes for over a decade as I see it as one of the reasons for low patient activism, to which I will come back in the further sections of this chapter.

In order to properly illuminate the normative background of the legal regulations applicable to people with RD, it is important to remember that the regulations concerning people with disabilities also apply to a substantial group of RD patients. In Poland, protests of people with disabilities and their caregivers took place in 2014 and 2018, respectively. Both protests pointed to the difficulties that people with disabilities face, as well as were intended to advocate for raising the awareness about the lack of institutional support for the families with disabled children. Parents who decided to give up work and do not receive any salary (at the time of the protest) were eligible to receive PLN 1407 per month of care allowance (around 350 euros). Disabled children (regardless of their caregivers occupational status) were entitled to receive PLN 153 a month of "extra care allowance" (around 39 euros). After reaching adulthood, each disabled person (born or who became disabled as a child or a student) was eligible to receive PLN 774 per month of social benefit (around 185 euros) and "extra care allowance", but the parents would lose the care allowance. Thus, the situation of families with adult disabled children was often extremely difficult as no other family benefits applied, such as the flagship government programme "500+ Family" ("Rodzina 500+"), even though they were still unable to accept full-time jobs as they were still primary caregivers. The "500+ Family" programme was launched on 1 April 2016. An allowance of PLN 500 per month is paid, regardless of the family's income, for each child up to the age of 18, also in a foster family, in a family-type children's home and a family-type

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[39] "Narodowy Plan ds. Chorób Rzadkich najpóźniej do 30 czerwca". *Medexpress* (04.03.2020). Available at: https://www.medexpress.pl/narodowy-plan-ds-chorob-rzadkich-najpozniej-do-30-czerwca/76546 (accessed 20.07.2020).

[40] Ordinance of 25 March 2020 of the Minister of Health repealing the ordinance on the appointment of the Plenipotentiary of the Minister of Health for the implementation of the National Plan for Rare Diseases [Zarządzenie Ministra Zdrowia z dnia 25 marca 2020 r. uchylające zarządzenie w sprawie ustanowienia Pełnomocnika Ministra Zdrowia do spraw wdrażania Narodowego Planu dla Chorób Rzadkich]. *Dziennik Urzędowy Ministra Zdrowia* 2020, item 26.

educational care facility.[41] In 2014 the Polish Constitutional Tribunal deemed the law regulating benefits for disabled children unconstitutional, as it discriminated disabled people over 18 years old, but the law remained unchanged. Demands raised by the protesting families included an extra PLN 500 (120 euros) monthly for those incapable of independent existence after the age of 18 and the levelling of social allowance to the sum of the lowest allowance of the Polish Social Insurance Institution (ZUS) for those permanently unable to work, and then gradually increase it to the social minimum, calculated for a household with a disabled person. The protesters also demanded a physical rehabilitation allowance and better access to healthcare. They also pointed to the fact that people with disabilities in Poland are a heterogeneous group and want to be better suited to meet their varying needs according to the type of disability. Both protests failed to bring substantial legislative changes, with further reinforcement of the familialism of the social policy. According to Sigrid Leitner, "familialism" is used to describe the caring function of the family as an important welfare production resource. It underlines the special role of the family in care – especially for children, elderly and the disabled.[42]

Sigrid Leitner proposed a typology consisting of four ideal types of familialism. She distinguishes explicit familialism, optional familialism, implicit familialism and de-familialism to examine state policies actively aiming at strengthening the family in its caring function for children, the elderly and the handicapped. Leitner's typology shows the extent to which welfare states use the resources of care provided mostly free of charge by the female relatives and the extent to which states actively provide care alternatives.[43] Using her typology, we could say that Poland is close to the implicit familialism model, where the state strengthens the family in caring roles (at least discursively), but also fails to provide any public or market driven alternative to family care, by which it reinforces the family as a primary care provider. In the absence of the regulations designed specifically for rare diseases, parents are trying to use other legal means to advocate for their children's best interest using the regulations concerning people with disabilities. One of the regulations facilitating care and access to specialist therapy came into force in January 2017 as part of the conservative anti-choice agenda of the Law and Justice government.[44] The so-called "For-life Act" promised for example: establishment of coordinating rehabilitation and care centres with particular

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[41] Ministry of Family, Labour and Social Policy, *"Family 500+" programme*. Available at: https://www.gov.pl/web/family/family-500-programme (accessed 30.06.2020).

[42] Sigrid Leitner, "Varieties of familialism: The caring function of the family in comparative perspective". *European Societies* 5 (2003), pp. 353–375.

[43] Ibidem, pp. 358–359.

[44] Act of 4 November 2016 on Support for Pregnant Women and Families "For life" [Ustawa z dnia 4 listopada 2016 r. o wsparciu kobiet w ciąży i rodzin "Za życiem"]. *Journal of Laws of the Republic of Poland* 2016, item 1860.

emphasis on early support for children's development from the moment of detection of disability or the risk of disability. It also proposed several innovations for the caregivers: to provide respite care for parents or guardians (120 hours) and to support professional activation and employment of carers and family members of people with disabilities.[45] In terms of everyday facilitation it guaranteed: priority in providing specialist healthcare services, psychological assistance for parents, therapeutic rehabilitation, medical devices such as diaper pants, catheters, prostheses – based on the order of an authorised person, and priority purchase of drugs. Needless to say, some of the ideas enlisted in the bill remain unfulfilled. Detailed analysis of the bill itself is beyond the scope of this chapter, but it is important to note that this bill covers all people with disability certificates. Nevertheless, it guaranteed priority in the access to specialist healthcare also for people with rare diseases.

In the following sections of this chapter, I briefly present the results of my research. First, I discuss the impact of (non)existing legal regulations on individuals, then I present the data about obtaining the disability certificate, and later I show the process of transition from paediatric to adult-centred healthcare systems.

4. Methodology and data

4.1. Study background

The study was carried out as part of the research project "An Anthropology of Rare Diseases: A Study of the Baltic Sea Region" sponsored by the National Science Centre (Poland, grant number: 2017/26/E/HS3/00291) aiming at examining the daily experiences of people with rare metabolic disorders and their family members in three countries around the Baltic Sea – Finland, Poland and Sweden. In this article, I use only the data gathered from Poland.

4.2. Participants

The families were recruited for this study through three Facebook support groups, during food preparation workshops and through the dietician working at The Children's Memorial Health Institute. Fourteen parents were interviewed in their homes, public places, and/or due to the COVID-19 pandemic, via an online communicator (chosen according to the participant's preference). The interviews took between 70 and 240 minutes each. The interviews provided

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[45] Office of the Government Plenipotentiary for People with Disabilities, *Informator Programu "Za życiem"*. Available at: http://www.niepelnosprawni.gov.pl/container/za-zyciem/Informator%20Za%20zyciem.pdf (accessed 30.06.2020).

the details about the family's history of dealing with the disorder, the referral process and the families' contacts with the healthcare system, incorporating their views on the legal regulations and experiences with being subjected to it. Secondary data was gathered through observation of online support groups for people affected by rare metabolic disorders. Additional background data was gathered through interviews with physicians, dietitians and representatives of patient advocacy organisations.

4.3. Coding

All interviews were recorded, transcribed verbatim and entered into the ATLAS.ti program. Some codes were formulated prior to reading the interviews, and later the analysis was iterative as the codes were developed inductively, along with successive readings of the transcripts. Sections of text were selected and coded on the basis of their relevance to the topics of legal regulations, National Plans for Rare Diseases, demands concerning the changes in law. Finally, I reviewed the data and re-read the transcripts to ensure identification of all examples that match the codes and subcodes.

4.4. Statement of ethical review

The data for this chapter was gathered as a part of the research project "An Anthropology of Rare Diseases. A Study of the Baltic Sea", conducted at the Institute of Philosophy and Sociology, Polish Academy of Sciences (PAS) since 2018. There was no formalised ethical review process for social sciences within the Institute comparable to, for instance, the US Institutional Review Boards at the time of research commencement. Thus, ethical clearance for conducting ethnographic research in Poland was provided primarily through the peer-review process of the funding organisation, i.e. the National Science Centre in Poland. Additionally, the ethicality of doctoral and postdoctoral research within the project has been ensured by the Principal Investigator of the project, Małgorzata Rajtar, PhD, Associate Professor at the Institute of Philosophy and Sociology, Polish Academy of Sciences.

Research has been conducted in accordance with the recommendations for anthropological research stated in the American Anthropological Association Statement on Ethics[46] and the Association of Social Anthropologists of the UK

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[46] American Anthropological Association, *Statement on Ethics* (2012). Available at: https://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=22869&navItemNumber=652 (accessed 30.06.2020).

and the Commonwealth Guidelines for good research practice,[47] as well as the Recommendations for Research with Humans of the National Science Centre.[48]

5. Results

5.1. National Plans for Rare Diseases

Knowledge about the National Plan for Rare Diseases or, more accurately, about the project of the National Plan for Rare Diseases, is far less widespread among the interviewed parents than among other actors (doctors, representatives of patients' organisations) involved in the shaping of the medical landscape concerning rare disorders in Poland. A surprising number of parents heard about the NPRD for the first time from the researchers. It is important to note at this point that the situation would be possibly different if patients for whom medical treatment is available were included in the interviewed sample, as they seem to have more tools for immediate goal-oriented patient activism.

It seems reasonable that most of the studies within the subfield of sociology of law focus on people who actively exercise their rights – through social movements, lawsuits, etc. I find it necessary, though, to also include people who seemed indifferent to the legal network shaping their immediate healthcare situation, in particular people who were unaware of the NPRD. People who seemingly did not have a high "legal consciousness". This term is used by scholars to identify what meanings of law circulate in the social relations. According to Silbey, "legal consciousness usually refers to micro level social action, specifically the ways in which individuals interpret and mobilise legal meanings and signs".[49] David Engel adds that individual rights' consciousness "derives from the intersections of a person's life experience with the particular interpretive frameworks that are available in the social environment".[50] Here, I follow the advice from Michael McCann about conducting "horizontal ethnographic studies of how rights consciousness develops out of practical experience

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[47] Association of Social Anthropologists of the UK and the Commonwealth, *Ethical Guidelines for good research practice (2011)*. Available at: https://www.theasa.org/ethics/ (accessed 30.06.2020).

[48] Narodowe Centrum Nauki, *Zalecenia Rady NCN dotyczące badań z udziałem ludzi* (2017). Available at: https://www.ncn.gov.pl/sites/default/files/pliki/2016_zalecenia_Rady_NCN_dot_etyki_badan.pdf (accessed 30.06.2020).

[49] Susan Silbey, "Legal culture and legal consciousness". In: James D. Wright (ed.), *International Encyclopedia of the Social & Behavioral Sciences*. Amsterdam 2001, pp. 8623–8629.

[50] David Engel, "Vertical and horizontal perspectives on rights consciousness". *Indiana Journal of Global Legal Studies* 19 (2012), p. 423.

in everyday social contexts"[51] and observe several individuals to examine the "legal consciousness" of the interviewed parents and its implications. I try to include interlocutors with a limited knowledge about the NPRD in order to achieve a more horizontal study.

As it has been pointed out already, Polish society can be characterised by a low level of "legal consciousness" and people's passivity and fear in seeking to uphold their rights.[52] It seems that this observation also applies to patients and their parents. Several interviews showed lack of initiative in self-assembling and disappointment in the type of help provided by patient advocacy organisations. It is interesting to note here that, in that regard, my data significantly differs from other known case studies – for example, Huyard[53] observed that French patients and their family members were eager to network with other people afflicted by the same or even another rare disease. She also noticed that, for patients and parents, disease-related associations played a crucial role, which to her constituted a distinctive trait of rare diseases. Similarly, Callon and Rabeharisoa show how patients associated in the French Association of Neuromuscular Disease actively contribute to shaping and re-shaping the relations between scientific research and political identities and how they skilfully build their position as legitimate stakeholders.[54] The reasons for such big differences in patients' attitudes requires further research.

Hence, more attention should be paid to educating parents about their rights (not only at national, but also European level) in order to enable better advocating for their children's interests and facilitate making claims about the lacking regulations. One of the ways to overcome this challenge would be to increase activity of patient advocacy groups in that sphere.

Patients affected by an RD experience a lot of difficulties not only in everyday life but also during medical encounters. Empirical research shows that we can talk about "historical revolution in the nature of doctor-patient relations",[55] however

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[51] Michael McCann, "Expanding the Horizons of horizontal inquiry into rights consciousness: An engagement with David Engel". *Indiana Journal of Global Legal Studies* 19 (2012), p. 467.

[52] Łukasz Bojarski, *Country report. Non-discrimination. Transposition and implementation at national level of Council Directives 2000/43 and 2000/78: Poland. Reporting period 1 January 2018 – 31 December 2018*. Warsaw 2019, pp. 1–156.

[53] Caroline Huyard, "What, if anything, is specific about having a rare disorder? Patients' judgements on being ill and being rare". *Health Expectations* 12 (2009), pp. 361–70.

[54] Michel Callon, Vololona Rabeharisoa, "The growing engagement of emergent concerned groups in political and economic life: Lessons from the French Association of Neuromuscular Disease Patients". *Science, Technology, & Human Values* 33 (2008), pp. 230–261.

[55] Susanna Trnka, *One Blue Child Asthma, Responsibility, and the Politics of Global Health*. Stanford 2017, p. 24.

the picture of new relations is heterogeneous and context-specific. On the patient's side, changes include striving for increased control and responsibility for their own health, on the professional's side, they cover transformation in medical authority and expertise. While for example American patients four decades ago seemed to prefer the physician to dominate decision making processes and be the sole provider of the expert information,[56] in the case of RDs often the patient or parent is forced to become knowledgeable about the disease. Unusual roles may cause difficulties in patient-physician interactions,[57] and not always lead to the best medical outcomes. Research by Trnka about New Zealander doctors working with asthma afflicted patients shows the tension created by the new "patient-expert" model – while doctors are eager to empower patients to be more responsible for the therapeutic procedures, they also need to make sure that necessary care and medical supervision is leading to satisfactory results.[58] She also shows the shortcomings of the patient empowerment movement in situations where structural issues remain unanswered and democratisation of patients comes to adhering to medication, with no critical reflection about the role of pharmaceutical companies.[59] Huyard, on the other hand, while looking at RD patients shows that, for them, expert medical knowledge was not a priority demand from the doctors – instead, they rather expected moral support and guidance about daily life activities. They wanted to be informed accurately enough about their condition in order to be able to proceed with their own life plans and goals.[60] She also observed that patients were aware of limitations of medical expertise, and they expected their doctors to admit it while seriously trying to address their problems.[61] The data gathered by other qualitative researchers such as Maciejewska-Mroczek, Radkowska-Walkowicz, Reiman and Rajtar seems to suggest that Polish patients might be reluctant towards patient empowerment and patient activism paradigms. They show that Polish patients and their parents faced with a rare genetic condition (Turner's syndrome) do not negotiate and do not engage in building meaningful strategies of resistance, which, according to the authors, is symptomatic for the relations within the Polish healthcare system and is informative about medicalisation and expert discourses present in Polish

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[56] Jack Ende, Lewis Kazis, Arlene Ash, Mark A. Moskowitz, "Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients". *Journal of General Internal Medicine* 4 (1989), pp. 23–30.

[57] Karolina Budych, Thomas M. Helms, Carsten Schultz, "How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction". *Health Policy* 105 (2012), pp. 154–164.

[58] Trnka, *One Blue*..., op. cit..

[59] Ibidem, p. 54.

[60] Huyard, "What, if anything...", op. cit., p. 366.

[61] Ibidem, p. 365.

society.[62] Several studies pointed to challenges around the empowerment paradigm and the patient expert paradigm (cf. for example Felt et al.[63]). While ethics of citizenship can be used by some expert patients, they also do experience frustration and lack of validation of their symptoms from the medical professionals. Taking into consideration an already marginal position of patients affected by rare inborn errors of metabolism, it is not surprising that not all of them find enough time, strength and resources to actively question and contest the organisation of healthcare.

It should be noted that numerous unsuccessful attempts to enact subsequent versions of the NPRD, followed by even further iterations, did not encourage possibly interested parents to become more active in this field. Rather, it became one of the numerous, anecdotal stories showing the state's inability to effectively execute particular tasks. The long and inconclusive legislative procedure created distrust of yet another promised version of the National Plan for Rare Diseases.

5.2. Obtaining a certificate of disability

Disability discourse falls into two broad categories: medical and social. The first one focuses on diagnosis and individual impairments, while the latter looks at demurring the social structures. While the division between medical and social models of disability is mostly political and offers oppositional perspectives, qualitative scholarship shows that they are not necessarily mutually exclusive in practice.[64] Research about families with disabled children provides examples of parental manoeuvring strategies between these two axes in order to achieve the best opportunities for their children.[65]

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[62] Radkowska-Walkowicz, Maciejewska-Mroczek, Reimann (eds.), *Zespół Turnera*, op. cit.; Rajtar, "Bioetyka...", op. cit.

[63] Ulrike Felt, Milena D. Bister, Michael Strassnig, Ursula Wagner, "Refusing the information paradigm: informed consent, medical research, and patient participation". *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 13 (2009), pp. 87–106.

[64] Tom Shakespeare, "Social models of disability and other life strategies". *Scandinavian Journal of Disability Research* 6 (2004), pp. 8–21; Bianca Manago, Jenny L. Davis, Carla Goar, "Discourse in action: Parents' use of medical and social models to resist disability stigma". *Social Science & Medicine* 187 (2017), pp. 169–177.

[65] Robert Blum, Dale Garell, Christopher H. Hodgman, Timothy W. Jorissen, Nancy A. Okinow, Donald P. Orr, Gail B. Slap, "Transition from child-centered to adult healthcare systems for adolescents with chronic conditions". *Journal of Adolescent Health* 14 (1993), pp. 570–576; Manago, Davis, Goar, "Discourse in action", op. cit.

Obtaining a disability certificate, despite being diagnosed with a rare inborn error of metabolism, proves to be another point on the patient journey where lack of additional legal regulations is painfully experienced. In Poland, disabled persons are eligible to obtain a certificate of disability specifying one of the three degrees of its severity – ranging from mild and moderate to profound. Certificates are issued in the first instance by the District Disability Evaluation Boards, and in the second, by the Provincial Disability Evaluation Boards.[66] Parents of children with a certificate of disability stating that the child requires constant support which makes the guardian unable to work are entitled to receive a monthly financial allowance. In 2020 the amount of monthly allowance was PLN 1,830 (around 415 euros). It is important to note that the increase of the allowance was the effect of the earlier mentioned protest, since the former financial support for families was even smaller. In order to obtain such a certificate, parents must gather all the required documents and appear before the Evaluation Board consisting of medical examiners. Observations of several support groups and interviews show that decisions about disability certificates vary significantly between different District and Provincial Boards. In order to be eligible for monthly financial support, the Board has to decide that there is:

7. the need for constant or sustained care or support of another person due to profoundly limited ability for independent existence;
8. the need of constant participation of the child's guardian in the process of treatment, rehabilitation and education.[67]

Financial allowance is granted only if two positive answers are obtained. As the latter point seems not to raise any controversies, obtaining a positive answer in point 7 is much more difficult and arbitrary. The interviewed parents complained that medical examiners lack knowledge about rare inborn errors of metabolism and the nature of these types of illnesses[68] and are prone to dismiss them as not being serious conditions. During an online discussion about troubles with obtaining disability certificate, one of the mothers recalled:

> The first time when we applied for [a certificate of] disability the doctor asked me if I was feeling good because there was nothing wrong with my child. So I just

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[66] Iwona Radlińska, Marta Bażydło, Beata Karakiewicz, "The rights of persons with disabilities in Poland". *Journal of Public Health, Nursing and Medical Rescue* 4 (2014), pp. 25–30.

[67] Regulation of 15 July 2003 of the Minister of Economy, Labour and Social Policy on disability and disability degree assesment [Rozporządzenie Ministra Gospodarki, Pracy i Polityki Społecznej z dnia 15 lipca 2003 r. w sprawie orzekania o niepełnosprawności i stopniu niepełnosprawności]. *Journal of Laws of the Republic of Poland* 2018, item 2027.

[68] Rajtar, "Normalised eating...", op. cit.

> pointed at the briefcase with all of my documents and nicely asked her if she was able to read. After a while, she looked at the documentation and I think she became embarrassed, as she didn't say another word.[69]

Similarly to what Huyard[70] observed, parents and patients do not expect all medical examiners to be highly knowledgeable about their condition – they expect, however, that they will offer them moral support and understanding. Parents find it difficult and frustrating to explain the necessity of resigning from work and the need to provide day-to-day care. For some Boards a genetic disorder requiring following a very strict dietary regimen, frequent visits in hospitals and the need to constantly observe the child is not profound enough to grant the approval for financial aid. Most of the questioned cases end up in court, where parents file an appeal and finally secure the right for the financial aid. Decision is not valid forever, though. Despite the inborn genetic nature of the disorders, certificates are granted over a varying amount of years. The "luckiest" parents receive it up to the moment when the child turns sixteen, while others have to renew the procedure every four or two years. Again, also in these procedures communities of trust serve as a substantial help and support – parents exchange information about each Board's proceedings and offer each other help in writing appeal requests. It is also possible to obtain professional legal assistance through some patient organisations such as Ars Vivendi, although the interlocutors discussed here did not mention using these resources.[71]

Another issue pointed out by the parents lies in the procedure of obtaining a certificate and the need to appear before the Board with the child, even though patients with rare inborn errors of metabolism are advised to avoid potentially risky gatherings of people. Some Boards allow procedures to take place in the absence (*in absentia*) of the patient (usually in the first year of life), others, however, require to see and examine the applicants each time, even in the high infectious season. One of the mothers expressed her concerns before visiting the Evaluation Board and asked other parents for their experiences. Extracts from that conversation read as follows:

> Zofia: I have a question concerning disability certificates. Do you take your kids to the Board or maybe someone managed to do it remotely? We will have to see the Board in January and I was wondering if someone with our condition managed

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[69] Online support group on Facebook, posted on 28.12.2017. Note: I deliberately do not use the exact name of the group and change the names of the members in order to secure anonymity of research participants.

[70] Huyard, "What, if anything...", op. cit.

[71] Ars Vivendi Association, *Statut* (28.02.2018). Available at: https://arsvivendi.org.pl/?Statut (accessed 30.06.2020).

> not to take the child due to the highly infectious time of the year and it is scary to go where the crowds are. And it is always crowded there.
>
> Maria: In the court, after appealing, I was able to be without my child, but when facing the District [Disability Evaluation Board] I had to take him, so that the doctor could examine him.
>
> Joanna: We had to take our child, despite the doctor's note on our application that it is vital to avoid crowds. [dissatisfied emojis] They just don't get it.
>
> Zofia: I thought that doctors are more sympathetic, but now when I see your responses, I see how naive I was…Shame, I try to do whatever is possible to avoid infections and here with this Evaluation – full of small kids, and half of them have a cold…[72]

It results in the feeling of being forced to take part in pointless procedures and irritation on the parents' side, as all the efforts of securing the child's health are put at risk.

Parents also discuss possible ways of forming a united front in fighting for their children's rights and systemic changes. Over the interviews, they recognised the inequalities and differences in the treatment by the Boards, also depending on their social and cultural capitals and abilities to discuss particular regulations applicable to their case. Many parents point to the lack of knowledge and skills to appeal their allowance rejection on their own and the need to seek professional legal advisors. Here, again, online support groups provide valuable information and confidence which enables them to confidently advocate for their children's best interests.[73] Unification of the procedures (regarding for example the *in absentia* procedure) as well as unification of the criteria according to which the certificate is granted need to be implemented in order to improve the current situation of patients with rare inborn errors of metabolism.

In Poland, the medical model of framing disability prevails, according to Kubicki,[74] in the experts' discourse which he perceives as an obstacle to obtaining emancipation of people with disabilities. I argue that, in this case, however, especially when the disability of the children is "not visible enough", referring to the medical model of disability can be a tool for re-claiming rights. The interviewed parents use mixed meanings extracted from social and medical models for strategic purposes – they point out everyday life examples of living with an IEM to explain

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[72] Online support group, Facebook, posted on 10.12.2018.

[73] Anna Chowaniec-Rylke, "'Lchad Poland' and the Fight Against Inequality". In: Maria Berghs, Kudakwashe Dube, Yahya El-Lahib, Tsitsi Chataika (eds.), *The Routledge Handbook of Disability Activism*. Abingdon, New York 2019, pp. 289–296.

[74] Paweł Kubicki, Rafał Bakalarczyk, Marek Mackiewicz-Ziccardi, "Protests of people with disabilities as examples of fledgling disability activism in Poland". *Canadian Journal of Disability Studies* 8 (2019), pp. 141–160.

atypical behaviours of their children and prove the need for acquiring a caregiver status. Even though having a "disabled"[75] child can be ambiguous for the parents, they still recognise that obtaining the certificate is the only way to ensure the best and the fastest healthcare (based on the so called "Pro-life" Act),[76] so, regardless of their views, they skilfully use experts' predilection for medical models.

4.3. Transition

Each year, thanks to early detection through the screening of newborn children and a growing body of knowledge about the nature of rare disorders, the number of affected patients surviving into adulthood is increasing. The previously fatal conditions turn into chronic and, as a result, new forms of care and patient-doctor interactions emerge.[77] Biomedically, "transition" is defined, somehow self-explanatorily, as a moment when a paediatric patient reaches the age of legal maturity and has to be transferred to adult-centred healthcare units. Within the adult healthcare system, patients are assumed to also have adult identity.[78] It is a process of managerial and medical nature. By contrast, medical sociology scholarship shows that transition is a longer and heterogeneous process starting with adolescents anticipating their transition long before it even takes place, but also demonstrates how it changes the way in which patients build their own identities and positionalities within the healthcare.[79]

Several challenges of medical nature occur in regard to transitioning patients. As Mazzucato et al. point out – coordinated expert teams, established in paediatric centres, do not necessarily exist in adult care settings; thus, more patients' energy needs to be invested in (re)creating such entities on their own after transition.[80] Moreover, expert knowledge about the course of the disease in adulthood is based on a limited number of cases due to previous early mortality; thus, medical teams lack the knowledge and necessary data. Also, some

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[75] Chowaniec-Rylke, *Posiłek co dwie...*, op. cit.

[76] Act of 4 November 2016..., op. cit.

[77] Katharine S. Steinbeck, Lynne Brodie, Susan J Towns, "Transition in chronic illness: who is going where?". *Journal of Paediatrics and Child Health* 44 (2008), pp. 478–482.

[78] Andrew Kennedy, Felicity Sloman, Jo A. Douglass, Susan M. Sawyer, "Young people with chronic illness: The approach to transition". *Internal Medicine Journal* 37 (2007), pp. 555–560.

[79] David Taylor, Michael Bury, "Chronic illness, expert patients and care transition". *Sociology of Health & Illness* 29 (2007), pp. 27–45.

[80] Monica Mazzucato, Laura Visonà Dalla Pozza, Cinzia Minichiello, Silvia Manea, Sara Barbieri, Ema Toto, Andrea Vianello, Paola Facchin, "The epidemiology of transition into adulthood of rare diseases patients: Results from a population-based registry". *International Journal of Environmental Research and Public Health* 15 (2018), pp. 1–13.

patients experience varying degrees of cognitive impairments, adding another level of complexity to the transition process.[81] Therefore, the need for establishing "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems"[82] known as transitional care, has been recognised at the international level.

Similarly, rare-disease patients in Poland, despite facing "usual" physical, psychological, and relational challenges characteristic for adolescence, face also greater challenges related to the necessity of changing their healthcare providers. As children, they experience relatively good healthcare, focused around one specialist and dietician at the specific hospital. When they turn eighteen, they are obliged to move from the paediatric to the adult healthcare system, regardless of various factors such as availability of appropriate medical facility, spatial distance, cognitive availability of the patient to manage their own therapy and psychological maturity to become the responsible agent.[83]

Currently, no regulations about the transition for RD patients exist or apply, thus the responsibility for ensuring smooth transition relies solely on the patient and his or her family. In exceptional but justified cases, the National Health Fund may allow continuation of treatment by adolescent patients at the same paediatric hospital. However, such short-term solutions are not widespread and usually used only in a direct need of hospitalisation, and therefore cannot be treated as part of widely available options.

Difficulties related to the transition have been raised during the interviews not only with patients' parents but also with medical professionals. Doctors responsible for adult patients pointed out that some of the patients arrive in their clinic by accident as there are no guidelines where to refer adolescent patients, and the task of finding the right hospital and specialist relies greatly on the patients and their economic and social capitals. Long breaks in therapy and lack of medical supervision can cause severe health consequences and may undo the results achieved during the previous years of therapy.

Transition is a difficult moment also for the parents of affected children. Since from the very beginning they can rely on the communities of trust, composed of parents dealing with the same diagnosis, questions of managing everyday problems in the phase of childhood are relatively available (through phone calls and social media). Closed Facebook support groups serve as a "means

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[81] Ibidem.

[82] Blum et al., *Transition*..., op. cit.

[83] For similarities experienced by patients with Turner Syndrome, cf. Maciejewska-Mroczek, Radkowska-Walkowicz, Reimann (eds.), *Zespół Turnera*, op. cit.

of maintaining control against an unknown".[84] As the number of patients with real-life experience of adolescence is extremely limited, this culturally established reference model also fails to provide reliable information. Neonatal screening for genetic disorders is a relatively new tool in the public healthcare practice. In Poland, screening for phenylketonuria (PKU) has been available since 1985, but some of the rare inborn errors of metabolism were not added to the screening panel until 2013.[85] Knowledge about available healthcare for adults is not widespread, parents are also aware of the fact how limited medical data there is. They are also aware that their legal situation will be even worse when they will not be able to enjoy at least these regulations available for minor patients. As one of the interviewed mothers put it:

> If they did something for all of the people with RDs, that would be great, no? For adults for example, because when he (son of the interviewee – author's note) grows up, I don't know what it will look like, as long as he's a child and there is this "pro-life"[86] bill it's all right now, but what when he is 18 years old, what will happen then? He will be stuck in queues for months?!

The legal void which RD adult patients enter after reaching maturity adds up to the already difficult situation of affected families, causing additional distress and anxiety.

6. Conclusion

The objective of this chapter was to explore experiences of the parents of children affected by rare inborn errors of metabolism in regard to (lack of) legal regulations concerning this particular group of patients. It aimed at mapping and providing ethnographically grounded data showing specific moments of the patients' journey in the healthcare system, when access to it is limited or hindered due to the lack of appropriate regulations, which according to the EU Recommendation should have been in place since 2013.

As this chapter shows, delay in preparation and implementation of the specific regulations for RD patients, in a form of the National Plan for Rare Diseases, causes several consequences. First of all, affected patients experience inequality in the access to the appropriate healthcare, also in comparison to other

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[84] Pauline Herbst, "Action stations: Biological cosmopolitanism at play on online support groups for genetic disorders". *Sites: A Journal of Social Anthropology and Cultural Studies* 13 (2016), p. 176.

[85] Jarosław Gumienny, "Newborn screening in the Polish population". *Medycyna Ogólna i Nauki o Zdrowiu* 22 (2016), pp. 169–175.

[86] Act of 4 November 2016..., op. cit.

EU countries. Moreover, lack of regulations for RD patients results in the lack of equity in Polish healthcare. Unregulated situations can lead to deterioration of the general health condition of affected people, also increasing the costs of healthcare in the future. On a more personal level, it adds up to an already difficult situation of affected families, causing additional unnecessary distress and anxiety.

Situation of patients and their families with IEM is the result of the intersection between disability and particular genetic citizenship. Families overburdened with the need to provide day-to-day care and manage healthcare find it difficult to also advocate for the long-term solutions, instead prefer to pragmatically prioritise on current tasks and challenges. Constant uncertainty discourages parents, undermining the potential of the patient empowerment paradigm. Therefore, the need for increased action from the patient advocacy organisations should be recognised.

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Anna Hucko

Who's the captain? Competencies of family doctors as healthcare coordinators in the light of the programme of specialisation and international recommendations

Introductory remarks

The healthcare system in Poland, as well as in other countries, suffers from health workforce shortages, which result in a limited access to health services. The idea of introducing a new position of a healthcare coordinator in health organisations is considered to be, together with the change of management strategy, a step towards rationalisation of healthcare delivery. Since it is not exactly clear what the core responsibilities of a healthcare coordinator are, many questions on the effectiveness of this reform can be posed. One of them, regarding the role of the healthcare coordinator in primary healthcare, is: What are the coordinator's competencies and how they relate to the role of family physician? During my research, I have identified an inconsistency in terms introduced by the national legislation and definitions found in the literature review and common use. According to the Primary Healthcare Act (PHC)[1] a doctor providing PHC is obliged to ensure the coordination of healthcare delivery, which I recognise as an equivalent to coordinating healthcare delivery and fulfilling the role of a healthcare coordinator. The literature review and common ground offer a different view on the role of a healthcare coordinator and define it as broadened function of a secretary. Shaped this way, it may answer the needs of other medical specialties such as oncology, where the coordinator's role can be limited to connecting patients with other healthcare system's resources. But primary healthcare, with a much greater scope that includes very different aspects of one's health, calls for a coordinator whose role is managerial and respectively broader. Given that, family physicians' competencies are perfectly fit for the role of healthcare coordinators.

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[1] Act of 27 October 2017 on Primary Healthcare [Ustawa z dn. 27 października 2017 o podstawowej opiece zdrowotnej]. *Journal of Laws of the Republic of Poland* 2017, item 2217.

1. Introduction

Introducing a DMP model (*disease management pathways*) of coordinated/integrated health services delivery (CIHSD)[2] in primary healthcare (PHC) in Poland is a change of strategy in management of the healthcare system. It is consistent with the direction in which most of the systems are being globally transformed. It is, at the same time, a manifestation of a shift in the paradigm in healthcare management. The new perspective is fuelled by new health challenges (aging populations, non-communicable and chronic diseases, social environment)[3] and by concepts such as patient empowerment, personalisation of care, bio-psycho-social approach to care, promotion of health and wellbeing. The traditional approach is concentrated on hospital-centred acute care and treating only one disease, while the population-based approach focuses on personalised, integrated services. The shift from a traditional to a new approach has now been formally expressed in the Primary Healthcare Act adopted on 27 October 2017.[4] Due to certain agreed delays, at the moment this article was being written, the model of coordinated care called "POZ Plus" had just entered into force.

2. Coordination as a management function

According to the Act, a PHC doctor is now obliged to ensure coordination of care. According to Koźmiński et al.,[5] management means ensuring the conditions for an organisation to function as intended. Ensuring coordination is equivalent to coordinating understood as a function of management, but in a broader sense than in classical Fayol's interpretation.

The Act defines coordination of healthcare delivery as an integration of health service delivery at all of its stages, including all its elements, with the IT solutions support and with respect to its quality and efficiency.[6] According to Hermanowski and Rutkowski,[7] CIHSD is a pro-quality strategy for managing the healthcare

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[2] Guus Schrijvers, *Integrated care. Better and cheaper.* Amsterdam 2016. Polish version: Sylwia Szafraniec-Buryło (ed.), *Opieka koordynowana. Lepiej i taniej.* Warsaw 2017

[3] Alma-Ata Declaration. International Conference on Primary Healthcare. Alma-Ata, 6–12 September 1978; Astana Declaration. Global Conference on Primary Health Care, From Alma-Ata towards Universal Health Coverage and the Sustainable Development Goals. Astana, Kazakhstan, 25–26 October 2018.

[4] Ibidem.

[5] Dariusz Jemielniak, Andrzej K. Koźmiński, Dominika Latusek-Jurczak, *Zasady zarządzania*. Warsaw 2014.

[6] Act of 27 October 2017..., op. cit.

[7] Tomasz Hermanowski, Jakub Rutkowski, "Zintegrowana opieka zdrowotna. Zarys problematyki". *Zeszyty Naukowe Politechniki Śląskiej. Organizacja i Zarządzanie* 83 (2015), pp. 225–233.

system in which an agent (as understood by the New Institutional Economy) plays a vital role between the system's stakeholders. The World Health Organisation (WHO) defines the CIHSD as the idea of connecting resources with the process of delivering care and with management and organisation of diagnostics, therapy, rehabilitation and health promotion.[8] Longest and Brook's definition of an organisation ensuring coordination states that it: "provides and arranges to provide a coordinated continuum of services to a defined population and is willing to be held clinically and fiscally accountable for the outcomes and the health status of the population served".[9] Coordinated care has three results to attain: better patient's satisfaction, improvement in the population's health status, and minimising the costs of care.

These definitions are prerequisites to understanding coordination as managing the whole process of care within an organisation (general practice in this case) by a coordinator performing a managerial role. In this sense, coordination comprises all other management functions: planning, organising, coordinating and controlling, according to classical Fayol's definition.

Longest claims that introducing such integration (coordination) changes the role of senior managers of healthcare organisations by redefining their competencies, and that the scope of this change may differ depending on the work itself and the work settings.[10] The literature also underlines the necessity to redefine the role of family doctors required to coordinate the care and stresses the importance of their coordinating role.[11] I redefine the role of family doctors by adding to the all already performed a new one – the managerial role of a healthcare coordinator. I develop the matrix to present a full range of their competencies arising from these indicated roles. It will show the scope of their changed (if any change is actually necessary) competencies to perform the managerial role of a coordinator. In the following research, I use the matrix as a tool to assess family physicians' competencies being proven in practice.

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[8] WHO European Office for Integrated, Health Care Services, *Integrated Care, Working Definition*, 2001.

[9] Beaufort B. Longest, Daniel H. Brooks, "Managerial competence at senior levels of integrated delivery systems/Practitioner response". *Journal of Healthcare Management* 43 (1998), pp. 115–133.

[10] Ibidem.

[11] Agata Stefanowicz, "Obowiązki lekarza rodzinnego w świetle projektu ustawy o podstawowej opiece zdrowotnej". *Medyczna Wokanda* 9 (2017), pp. 171–177; Katharina V. Stein, *Opieka koordynowana na świecie. Przykłady mające pomóc usprawnić (podstawową) opiekę zdrowotną w Polsce*. Warsaw 2016; Hermanowski, Rutkowski, "Zintegrowana...," op. cit.

3. The role of a healthcare coordinator

Along with this broad definition of coordination as a management function, the role of a healthcare coordinator becomes central for discharging it. A coordinator fulfilling the function of management plays a managerial role. Fero et al.[12] state that the roles and functions of a coordinator depend on the setting in which the care is provided, the adopted model of coordination and the goals of services integration. They present a broad range of different types of the roles that may be adopted by a coordinator, among others communicator, resource manager, gatekeeper, facilitator, financial adviser and physician. Kowalska-Bobko et al.[13] identify the role of a coordinator (but regarding those who work so far within other medical specialties like oncology) with a broadened role of a secretary. This understanding is also present on the common ground, such as job descriptions in advertisements.[14]

Introduction of the CIHSD in PHC caused the emergence of a new managerial role of a coordinator. The setting of primary healthcare in Poland implies the fact that out of organisational issues and because of the specifics of PHC and also the legal requirements,[15] the role of a coordinator will be formally or informally (if the doctor decides to hire a person for the secretary-understood position of a coordinator) taken on by a physician.

Besides ensuring coordination, primary care physician is also obliged to manage the PHC team (doctor, nurse and midwife) that conducts tasks such as coordination of care, which means that the doctor stays superior to other employees. This also comprises coordination as a management function.

Fero et al.[16] consider the coordinator as a linchpin[17] for the healthcare system. The definition consistent with the understanding of coordination should assume that the coordinator is managing the delivery of care within a given population

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[12] Laura J. Fero, Charlotte A. Herrick, Jie Hu, *Introduction to Care Coordination and Nursing Management*. Sudbury 2011.

[13] Iwona Kowalska-Bobko, Małgorzata Gałązka-Sobotka, Aldona Frączkiewicz-Wronka, Katarzyna Badora-Musiał, Beata Buchelt, "Skill mix in medical and about medical professions". *Medycyna Pracy* 71 (2020), pp. 337–352.

[14] *Health Care Coordinator: Job Description, Duties and Requirements* (28.9.2019). Available at: https://study.com/articles/Health_Care_Coordinator_Job_Description_Duties_and_Requirements.html (accessed 26.10.2020).

[15] Regulation of 27 November 2019 of the Minister of Health on the scope of tasks of a primary care physician, primary care nurse and primary care midwife [Rozporządzenie Ministra Zdrowia z dnia 27 listopada 2019 r. w sprawie zakresu zadań lekarza podstawowej opieki zdrowotnej, pielęgniarki podstawowej opieki zdrowotnej i położnej podstawowej opieki zdrowotnej]. *Journal of Laws of the Republic of Poland* 2019, item 2335.

[16] Fero et al., *Introduction to Care*..., op. cit.

[17] Ibidem.

in a way guaranteeing complexity, continuity and efficiency of the whole process. Thus, I define the coordinator as a person who, by using his/her knowledge about health, his/her ability to take action to promote health and to counteract the disease, acts in a predictive, comprehensive, purposeful and efficient manner in favour of the population for which they care for.

4. Competencies of family doctors as healthcare coordinators – theoretical model

I based the model of competencies developed as a theoretical foundation of the matrix on the assumption that the definition of competencies of family doctors as healthcare coordinators has to be as wide as possible. This means that it should include elements comprised by this specific role: being at the same time a physician, a coordinator and a manager, and proving appropriate competencies. To make it visible, I suggest framing the definition on three dimensions. Each of them reflects a crucial aspect of their role as healthcare coordinators and competencies that arise from this aspect. The first dimension defines the competencies of physicians with a special regard to family doctors, what is emphasised the most here is an equal importance of formal requirements regarding knowledge and abilities and socio-psychological aspects of this role. A big part of these aspects relate to traits defined as distinguishing characteristics and qualities, especially of personal nature.[18] The second dimension defines the core competencies needed for integrated health services delivery, whereas the third refers to managerial competencies. In the second and the third dimensions, the competencies are perceived as tools for improving the outcomes and attaining the results. In the third dimension, what is very important is stressing in the definition of managerial competencies is that they refer to the process of care, and not the organisation as a subject to management, which means that managing goes beyond the limits of an organisation. Table 1 presents the definitions of the competencies of physicians, coordinators and healthcare managers' found in the literature.

I offer the definition of the competencies of family doctors' as healthcare coordinators of the three outlined dimensions with reference to the definitions presented in Table 1. The competencies of family doctors as healthcare coordinators represent a complex set of formally required knowledge and abilities to deliver the best possible personalised, integrated and cost-effective healthcare, as well as personal characteristics comprised of attitudes, traits, motives, values and life experiences, which at the same time determine the acquiring and manifesting of competencies. Using this definition, I have built a matrix of competencies.

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[18] Neeraj Kak, Burt Burkhalter, Meriann Cooper, "Measuring the competence of healthcare providers". *Operations Research Issue Paper* 2, 1 (2001), pp. 1–28.

Table 1. Definitions of competencies

Competencies	Definitions
Physician's/family physician's competencies	Miller: the ability to use knowledge, abilities and attitudes in a given, defined situation;
Healthcare coordinator's competencies	Langins and Borgermans: an essential complex of knowledge based acts that combine and mobilise knowledge, skills and attitudes with the existing and available resources to ensure safe and quality outcomes for patients and populations. Competencies require a certain level of social an emotional intelligence that are as much flexible as they are habitual and judicious;
Manager's competencies	Shortell and Kaluzny: knowledge, abilities and understanding required to manage interdependent professional task teams delivering services within the cycle of care.

Source: own elaboration based on: George E. Miller, "The assessment of clinical skills/competence/performance." *Academic Medicine* 65, 1 (1990), pp. 63–67; Margrieta Langins, Liesbeth Borgermans, *Strenghtening a Competent Health Workforcefor the Provision of Coordinated/Integrated Health Services*. Copenhagen 2015; Stephen M. Shortell, Arnold D. Kaluzny, *Podstawy zarządzania opieką zdrowotną*. Kraków 2001.

5. Methods

Several steps have been planned to develop a matrix of competencies. This article presents the results of the second stage of the research conducted between March and May 2020. The method used was qualitative content analysis. The subject of the research was the set of competencies of family medicine specialists deriving from one source, which is the Programme of Specialisation[19] and recommendations of the Family Doctors' College in Poland based on the EURACT Educational Agenda[20] (Set-2). Set-2 was compared with the CIHSD core competencies recommended by the WHO[21] (Set-1). I compare the sets to assess their mutual relationship.

The Programme of Specialisation in Family Medicine was written in 2014 and updated in 2018. It is being taught by an institution accredited by the Health Ministry, which is the Centrum Medyczne Kształcenia

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[19] Centrum Medycznego Kształcenia Podyplomowego, *Program Specjalizacji w dziedzinie Medycyny Rodzinnej dla lekarzy nieposiadających odpowiedniej specjalizacji I lub II stopnia, lub tytułu specjalisty w odpowiedniej dziedzinie medycyny, lub zrealizowanego i zaliczonego odpowiedniego modułu podstawowego*. Warsaw 2014.

[20] Adam Windak, Tomasz Tomasik, Witold Lukas (eds.), *Pryncypia nauczania medycyny rodzinnej w Polsce według EURACT Educational Agenda*. Kraków 2007.

[21] Langins, Borgermans, *Strengthening a Competent*..., op. cit.

Podyplomowego (CMKP, *Centre for Medical Postgraduate Education*). This is the broadest version of the programme of specialisation as it has been developed for physicians who have not acquired the first or second degree of an appropriate specialisation, have not been titled specialists in an appropriate medical specialty nor have completed an appropriate basic training. The Programme is based on the EURACT Educational Agenda – a document adopted by WONCA *(World Organisation of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians*) in 2005, which set several rules for teaching family medicine. It describes six core competencies of family physicians, which are supposed, as the programme outlines, to be acquired through specialisation training. The Programme is the source of competencies of family physicians, which compose Set-2 (shown in the right column in Table 2). Table 2 offers a comparison of the two sets of competencies – the first is WHO's 40 CIHSD core competencies and the second – 64 professional and seven key social competencies of family doctors. In both sets, the competencies are gathered in several categories (in the WHO Working Document, the notion of clusters is used, and here is understood as a category of competencies).

Table 3 shows the findings of the content analysis of the two sets of competencies. The numbers in the left column refer to each of the coordinator's competencies as listed in Set-1. The numbers in the right column indicate which of the physician's competencies from Set-2 correspond to those of the coordinator. The comparison shows that the competencies from first four clusters (patient advocacy, effective communication, team work and patient-centred care) listed in the first set (Set-1) find their corresponding competencies in the second set (Set-2). Overlapping competencies are in italics. Some competencies from Set-1 are overlapped by more than one competency form the second set (Set-2), which means that some of them were broader and some were narrower than the corresponding elements. Only the competencies grouped in the fifth cluster (5 – continuing learning) in Set-1 have no similar examples in Set-2 since continuing learning is considered as a determinant of competencies in the Programme of Specialisation (WHO recommendations consider continuing learning to be the last cluster of competencies). Competencies that overlap only partially are in bold print. Content analyses conducted at other stages of the research also revealed that, in comparison with the other identified sets of competencies (set of medical doctor's competencies, set of primary healthcare physician's competencies),[22] some of the coordinator's competencies do not find any overlapping examples.

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[22] Sets of competencies were identified in accordance to the criteria of the role played by family physician in the healthcare system (the role of a medical doctor, of a primary healthcare physician, a manager of a primary healthcare team). All of the sets are comprised in the matrix of family physician's competencies that was developed on the last stage of the research.

Table 2. Sets of competencies

Sets of family doctor’s competencies according to source materials	
WHO Regional Office for Europe Working Document “Strengthen a competent health workforce for the provision of coordinated/integrated health services”	CMKP’s The Programme of Specialisation in Family Medicine
Set-1 **Competencies for the CIHSD (coordinated/integrated health services delivery)**	**Set-2** **Family doctor’s core competencies**
1. Patient advocacy The ability to promote patients’ entitlement to ensure the best quality of care and empowering patients to become active participants of their health a. Advocate for the role of the patient, family members (if appropriate) in healthcare decisions b. Familiarise oneself with patients’ rights (to safe, high quality, affordable) health and social care with legal instruments: legal rights/civil/law; quasi-legal rights, patient charters, patients’ bill of rights, consumer protection policies c. Educate people on their right to healthcare and their benefits d. Encourage and promote patients’ broad social participation in governance of clinical setting: providing feedback on services received, building partnerships, engaging in political advocacy, promoting community leadership, collecting better data on social conditions and institutional factors, and enhancing communication for health equity e. Advocate for incorporation of patient outcomes into organisational strategies with a special focus on vulnerable populations f. Understand the effect of disparities on healthcare access and quality	1. Delivering primary healthcare a. Making decisions in regard to epidemiology concerning problems occurring in primary care b. Interpreting typical symptoms of diseases treated in primary care c. Identifying alarming symptoms d. Solving the whole range of patient’s problems e. Managing the process of care for chronic diseases f. Implementing effective preventive measures within primary care g. Diagnosing and treating acute diseases h. Providing assistance in case of life-threatening situations i. Organising palliative care j. Completing effective medical history, giving physical examinations and making use of additional laboratory tests k. Conducting pharmacological an non-pharmacological therapy l. Setting priorities for various problems m. Effectively collaborating and coordinating the PHC team n. Cooperating with other specialists o. Effectively using the healthcare system’s resources p. Communicating, advising and educating patients q. Organising general practice

2. Effective communication Ability to quickly establish rapport with patients and their family members in an emphatic and sensitive manner incorporating the patients' perceived and declared culture a. Demonstrate active, emphatic listening b. Engage family members and members of patient's circle of care in health assessments and disclosures, as per patient's approval c. Convey information in a jargon-free and non-judgmental manner d. Communicate care plan options to patient in a clear manner e. Adapt the style of communication that most appropriately takes into account the impact of health conditions on a patient's ability to process and understand information f. Ensure the flow and exchange of information among the patient, family members, (if appropriate) and relevant providers are complete g. Adapt services, including evidence-based inter-professional team approaches, and mobilise resources to suit the language, cultural norms, and individual preferences of patients and family members (if appropriate) h. Provide education to members of the team about the characteristics, healthcare needs, health behaviours, and views toward illness and treatment of diverse populations served in the treatment setting i. Provide health education (materials) that are appropriate to the communication style and literacy of the patients, family (if appropriate) and reinforce information provided verbally during healthcare visits	r. Managing information and medical documentation s. Knowing administrative procedures in the healthcare system t. Monitoring and improving quality of delivered care u. Ensuring systematically patient's and doctor's safety v. Ensuring, in a coordinated manner, equity in care delivery w. Maintaining appropriate relations with patients x. Effectively leading, negotiating and reaching a compromise 2. Delivering patient-centred care: a. Adopting personalized approach b. Considering problems in regard to patient's situation c. Understanding patient as a human being with respect to his values, development, objectives and expectations d. Taking into account all the familial, social and cultural conditions e. Keeping patient-oriented perspective during consultation f. Formulating conclusions in understandable way g. Making decisions with respect to patient's autonomy h. Being aware of subjectivity in medical relations i. Establishing partnership with a patient j. Balancing the distance and proximity with a patient k. Ensuring continuity of care 3. Specific problem solving: a. Making decisions depending on disease or problem dissemination in local community b. Determining the demographic and epidemiological situation of the population under care c. Making decisions in urgent situations d. Taking into account the right context of the patient's situation, including familial and social factors e. Using accessible diagnostic and therapeutic resources

Table 2 – continued

Sets of family doctor’s competencies according to source materials	
WHO Regional Office for Europe Working Document “Strengthen a competent health workforce for the provision of coordinated/integrated health services”	CMKP’s The Programme of Specialisation in Family Medicine
Set-1 **Competencies for the CIHSD (coordinated/integrated health services delivery)**	**Set-2** **Family doctor’s core competencies**
3. Team work Ability to function effectively as a member of an inter-professional team that includes the provider, patients and family members in a way that reflects an understanding of the team dynamic and group/team processes in building productive working relationships and is focused on health outcomes a. Clearly identify and support the roles and responsibilities of all team members, including patients. Represent one’s professional opinions and encourage other team members, including patients, to express their opinions and contribute to decision-making b. Resolve differences of opinion or conflicts quickly and without acrimony c. Demonstrate practicality, flexibility, and adaptability in the process of working with others, emphasising the achievement of treatment goals as opposed to rigid adherence to treatment models d. Link patients and family members (if appropriate) with the needed resources, including but not limited to specialised healthcare, rehabilitation and social services, peer support, financial assistance and transportation, following up to ensure that effective connections have been made. This includes arranging access to “patient navigation” services	f. Interpreting data gathered in medical history and physical examination, analysing patient documentation g. Engaging patient and/or his care givers in setting a treatment plan h. Implementing stepwise decision-making process i. Dealing with uncertainty in problem solving j. Making decisions in extraordinary situations k. Performing life-saving procedures l. Rationally employing diagnostic procedures 4. Comprehensive approach: a. Simultaneously managing the patient’s diverse problems b. Promoting health in all its aspects c. Including health promotion in day-to-day consultations d. Encouraging health promotion in the local community e. Balancing tensions between individual and community needs f. Coordinating elements of treatment, rehabilitation and palliative care 5. Orientation on local community: a. Understanding the population’s health needs through an epidemiological perspective

- e. Support patients in considering and accessing complementary and alternative services designed to support health and wellness
- f. Promote diversity among the providers working in inter-professional teams

4. People-centred care

Ability to create conditions for providing coordinated/integrated services focused on the patients and their families' needs, values and preferences along a continuum of care and throughout life

- a. Comprehend that effective care planning requires several discussions with the patient and other parties, over time
- b. Provide patient care that is timely, appropriate and effective for treating health problems and promoting health
- c. Screen for multi-morbidity and assess cognitive impairment, mental health problems including risky, harmful or dependent use of substances and harm to self or others, abuse, neglect, and domestic violence
- d. Assess the nature of the patient's family (if appropriate), social supports and other socio-economic resources that impact on patient's health
- e. Match and adjust the type and intensity of services to the needs of the patient, ensuring the timely and unduplicated provision of care
- f. Balance care plan with bio-psycho-and social interventions
- g. Incorporate the patient's wishes, beliefs and their history as part of the care plan, while minimising the extent to which provider preconceptions of illness and treatment obscure those expressed needs
- h. Manage alternative and conflicting views from family (if appropriate), carers, friends and members of the multidisciplinary team to maintain focus on patient wellbeing
- i. Use focused interventions to engage patients and increase their desire to improve health and adhere to care plans (e.g., motivational interviewing; motivational enhancement therapy)
- j. Assess treatment adherence in a non-judgmental manner

- b. Understanding interdependency between health and social services
- c. Understanding the influence of poverty, ethnicity and epidemiology on local health
- d. Being aware of health and healthcare disparities
- e. Knowing the structure of a healthcare system and its economic restraints
- f. Collaborating with other specialists engaged in social policy in regard to health, understanding their roles
- g. Understanding the importance of information regarding local community in order to ensure high quality care

6. Holistic approach:

- a. Employing the bio-psycho-social model in care delivery
- b. Being able to transform overall understanding into specific actions
- c. Understanding the patient's culture and existential background
- d. Understanding the patient's experiences, beliefs, values and expectations, which may affect health services

Social competencies:

- Employing the supreme principle of good for the patient
- Respecting a socially accepted system of values and deontological rules
- Being able to make decisions and to be held accountable for one's own actions and actions of the team one manages
- Being able to organise one's own work and smooth cooperation within the team
- Being able to establish an appropriate rapport with a patient and patient's family and caregivers with respect to self-dignity and cultural, ethnical and social differences
- Knowing psychological conditions underlying the patient-doctor relation
- Being able to provide information in the health status, prognosis and diagnostic and therapeutic procedures

Table 2 – continued

Sets of family doctor’s competencies according to source materials
WHO Regional Office for Europe Working Document “Strengthen a competent health workforce for the provision of coordinated/integrated health services” **Set-1** **Competencies for the CIHSD** **(coordinated/integrated health services delivery)**
5. Continuing learning Ability to demonstrate reflective practice, based on the best available evidence and to assess and continually improve the services delivered as an individual provider and as a member of an interprofessional team a. Participate in practice-based learning and improvement activities that involve investigation and evaluation of patient experiences, evidence, and resources b. Regularly assess and evaluate the experiences of patients, family members (if appropriate), with respect to quality of care and adjust the delivery of care as needed including measuring patient satisfaction and healthcare outcomes maintaining a no fault/no blame schemes c. Regularly engage in interdisciplinary training for staff d. Regularly engage in continuing professional development e. Implement and routinely monitor patient safety standards f. Participate in medical audits to check for rationality of care, billing and malpractice as needed g. Identify and mobilise evidence to inform practice and integrated care h. Participate in and conduct research where possible, emphasizing need for focus on patient experiences i. Contribute to practice-based learning and improvement activities in a way that mobilises evidence and research as much as end-user experiences j. Optimize the use of appropriate technology including e-health platforms which enables measurement and management of individual clinician, practice and system-wide performance on clinical processes and outcomes, e-prescription and electronic medication management, electronic health records, computer and web-based screening, assessment, and intervention tools, tele-health applications

Set-1 lists core competencies for coordinated/integrated health services delivery (CIHSD), Set-2 gathers family doctors’ core competencies.

Source: own elaboration based on: Margrieta Langins, Liesbeth Borgermans, *Strenghtening a Competent Health Workforcefor the Provision of Coordinated/Integrated Health Services*. Copenhagen 2015; Adam Windak, Tomasz Tomasik, Witold Lukas (eds.), *Pryncypia nauczania medycyny rodzinnej w Polsce według EURACT Educational Agenda*. Kraków 2007.

Table 3. Competencies overlapped. Results of the content analysis

Competencies overlapped	
Set-1	**Set-2**
1.a.	*2.g., 3.g.*
1.b.	*1.s.*
1.c.	*1.p., 4.b.*
1.d. building partnerships	*2.i.*
1. d. collecting data	*5.g.*
1.d. enhancing communication for health equity	*4.e.*
1.e.	*1.r., 1.t., 3.a., 5.c., 5.g.*
1.f.	*5.d.*
2.a.	*1.w., 2.a., 2.e., 2.i.*
2.b.	*2.g., 2.i.*
2.c.	*2.f.*
2.d.	*2.f., 2.i. as an element of partnership*
2.e.	*2.b., 2.c.*
2.f.	*1.r.*
2.g,	*2.d.*
2.h.	*1.m.*
2.i.	*1.p.*
3.a.	*1.x. as a part of leadership, 5.f. in regard to specialists' roles, 2.g., 2.h., 3.g. in regard to patients' roles*
3.b.	*1.b., 1.c., 1.j., 1.k., 1.l., 1.p., 2.c., 2.d., 2g., 2.h., 3 d., 3.g.* *1.x.*
3.c.	*1.l. regarding adherence to treatment plan, 1.k.*
3.d. practicality, flexibility, adaptability may be understood as personal attitudes determining competencies (as the Programme delineates)	
3.e.	*1.e. in specific cases*
3.f.	*3.e.*
3 g.	*2.k.*
4.a.	*1.m.*
4.b.	*3.g.*
4.c.	*1.a.-r., 1.t.*
4.d.	*1.b.-c., 2.b., 2.d., 3 b., 3.f.*
4.e.	*2.d.*
4.f.	*2.k., 4.a., 4.e., 4.f.*
4.g.	*6.a.*
4.h.	*6.d.*
4.i.	*1.x.*
4.j.	*4.c., 3.g., 1.f., 2.f.*
5.a.-j.	**Continuing learning understood as a determinant of competencies**

* Fragments in italics refer to distinguished parts of competency descriptions. ** Comments explore the interpretation of competency descriptions.

Source: own elaboration.

The analysis has demonstrated that the family physician's set of competencies (Set-2) is broader than the coordinator's set of competencies and absorbs four out of five clusters of competencies. At the same time, Set-2, as the results of other stages of the research show, represents the broadest collection of competencies included in the matrix of family physicians' competencies. This means that family physicians are fully competent to play the role of healthcare coordinators.

6. Results and discussion

At the first stage of the research, I analysed the competencies stemming from the national legislation on the CIHSD of a primary care physician as a healthcare coordinator (family doctor, among other specialists, is a primary care physician). I compared them with WHO's CIHSD core competencies. The comparison is justified by the assumption made that the family doctor performs the role of a healthcare coordinator and that is why WHO's CIHSD core competencies apply to describe this role. The results of the first stage currently waiting for publication indicate that the set of PHC doctor's competencies described by the legislator is narrow, and in relation to WHO's five clusters it is poorer and incomplete. The gap may be seen in the area of socio-psychological aspects of the coordinator's role, such as: practicality, elasticity, adaptability, understanding the aim of a discussion with the patient, social engagement, building partnership, special focus on vulnerable groups, understanding the effect of disparities on healthcare access, non-judgmental style of communication, input into the process of decision making and acquiring knowledge. The sets remain consistent regarding the following areas of competencies: cooperation, planning the care, assessing health status, risk, patient's environment, providing education, communicating the care plan, monitoring the quality and cost-effectiveness of the care.

The results of the second stage of my research show clearly that Set-2 is broader than Set-1, which shows that the range of family doctors' competencies is wide enough to overlap the CIHSD core competencies. This evidence leads to the conclusion that family doctors may perform the role of healthcare coordinators without the need for acquiring any new competencies. Moreover, it is probable that a number of family doctors are already coordinating the care for their patients – informally, they are healthcare coordinators.

The size of the set of family physicians' competencies implies a great role for them in the healthcare system, but it is not reflected neither in their practice nor in common perception. Entrusting family doctors with the managerial role of a healthcare coordinator may be considered "natural" – consistent with the objectives of family medicine, primary healthcare and coordinated health services provision.

7. Conclusion

In order to improve access to health services by introducing coordinated care with the key position of a healthcare coordinator, it is important to separate his or her managerial role from supportive responsibilities, which may be delegated to less competent workforce. Terminological inconsistency should be resolved by naming the healthcare coordinator the manager. The competencies of family physicians studied in this research overlap with both the manager's and the coordinator's competencies which make them suitable to play these roles. As the day-to-day practice shows, the help which they need and which could really improve the access to healthcare by taking over administrative tasks is an educated, self-reliant secretary.

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Katja Triller Vrtovec

Equal access to healthcare for low income population – Practical challenges of the healthcare reforms in Slovenia[1]

1. Introduction

In Slovenia, unmet needs of healthcare services are twice as high as the EU average. Therefore, there are ongoing efforts taking place to reform the healthcare system. The focus of the last healthcare reform, introduced by the National Assembly on 25 September 2019, was particularly aimed at improving financial access to healthcare for low income population. The first step of the reform involved including all healthcare services in the coverage of mandatory health insurance (MHI) and abolishing voluntary health insurance (VHI), which is purchased by about 95% of the population.[2] The second step of the reform consisted in transforming per capita voluntary health insurance premiums into income related mandatory social contributions. However, on 27 January 2020 the former Prime Minister stepped down and the healthcare reform was rejected by the National Assembly on 29 January 2020. On 13 March 2020 the new Government was constituted. The healthcare reform remains its main priority, especially since the unmet needs of healthcare services after the COVID-19 pandemic have, understandably, greatly increased.

2. Legal and structural background

The background will briefly describe the healthcare legal framework and the healthcare system in Slovenia. The Slovenian Constitution grants everyone the right to healthcare on the conditions provided by law. It asserts that

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[1] The views and opinions expressed in this article are those of the author and do not necessarily reflect the official policy of the Office of the Prime Minister nor of the Government of the Republic of Slovenia.

[2] OECD, European Observatory on Health Systems and Policies, *Slovenia: Country Health Profile 2019*. Paris, Brussels 2019. Available at: https://www.oecd-ilibrary.org/social-issues-migration-health/slovenia-country-health-profile-2019_79ba70a2-en (accessed 01.09.2020).

the rights to healthcare from public funds shall be provided by law and that the state shall regulate the MHI and shall ensure its proper functioning.[3] Virtually every resident of Slovenia is covered under the single compulsory insurance scheme. The relationship between the insured persons and the single national health insurance provider (The Health Insurance Institute, HIIS) is statutorily regulated, while the relationship between the HIIS and healthcare providers is contractually regulated.[4] The legal relationship between the HIIS and the insured persons is regulated by the Healthcare and Health Insurance Act (ZZVZZ), which stipulates that the MHI guarantees insured persons reimbursement of the cost of healthcare services in the percentage set by law.[5] On the primary level, for example, the MHI covers the full cost of preventive healthcare services and 80% of the cost of curative healthcare services. The implementing regulations of the HIIS restrict the share of healthcare costs for certain healthcare services covered by the MHI, to the extent that is not in conformity with the international public funding requirements. The European Code of Social Security Care prohibits beneficiary of primary outpatient healthcare services to bear the cost exceeding 25%. The HIIS nevertheless further restricted the coverage of non-emergency healthcare transportation and correction eyeglasses to only 10%.[6] About 95% of the population also purchases VHI, mainly to cover co-payments, which is the highest share in the EU.[7]

3. Objectives and methods of the study

In the paper, I first want to verify the assumption on which the former unsuccessful healthcare reform was based on. The assumption is that suboptimal access to healthcare in Slovenia is caused by financial reasons because healthcare services are too expensive. This assumption will be verified by the established methods of legal reasoning, such as linguistic method (when one refers to the meaning of the term in ordinary language), comparative method (when one

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[3] Ibidem.

[4] Katja Triller Vrtovec, "Healthcare Law". *Official Gazette*, Ljubljana 2019.

[5] Healthcare and Health Insurance Act [Zakon o zdravstvenem varstvu in zdravstvenem zavarovanju, ZZVZZ]. *Official Gazette of the Republic of Slovenia* Nos. 72/06 – uradno prečiščeno besedilo, 114/06 – ZUTPG, 91/07, 76/08, 62/10 – ZUPJS, 87/11, 40/12 – ZUJF, 21/13 – ZUTD-A, 91/13, 99/13 – ZUPJS-C, 99/13 – ZSVarPre-C, 111/13 – ZMEPIZ-1, 95/14 – ZUJF-C, 47/15 – ZZSDT, 61/17 – ZUPŠ, 64/17 – ZZDej-K, 36/19, 189/20 – ZFRO, 51/21, 159/21 and 196/21 – ZDOsk.

[6] Katja Triller Vrtovec, "Public policy changes in public funding of family doctors in Slovenia". *International Journal of Public Sector Performance Management, Special Issue on: Public Policies and the Development of Entrepreneurship*, in print.

[7] OECD, European Observatory on Health Systems and Policies, *Slovenia*, op. cit.

refers to the legal systems of other states), teleological method (when one refers to the goal or purpose of the rule), historical method and systematic method (when one refers to the place and context of the rule in the legal system and the relation with other rules).[8]

If the first objective of the study is validated by the stated legal methods, I intend to verify whether or not the former unsuccessful healthcare reform would actually improve overall access to healthcare for the Slovenian population. Conversely, if this objective of the study is not validated, I then want to determine the main reason for suboptimal access to healthcare in Slovenia. In general, access to healthcare services can be denied based on the criteria of time, location or price. *Healthcare availability* determines the situation where access to healthcare services is denied because of the waiting time for the service. *Healthcare affordability* determines the situation where access to healthcare is denied, because the service is too expensive for the patient. *Healthcare proximity* determines the situation where access to healthcare is denied, because the service is too far to travel to.[9]

If the proposed healthcare reform proves unlikely to improve overall access to healthcare, I will discuss the alternative means to improve access to healthcare for the total population that could be considered by the new Slovenian government.

4. Results of the study

4.1. Results of using the linguistic method

In order to verify the assumption that low income population has poor access to healthcare, one initially needs to define the term "low income population" and, secondly, the subjects that are required to pay mandatory social contributions and voluntary health insurance premiums for the low income population.

On the Slovenian national level, "low income population" is defined as "those unable to ensure funds for themselves and their family members in the amount of the minimum income due to reasons beyond their control", where the basic amount of minimum income is currently set at EUR 402 per person per month (Articles 6 and 8 of ZSVarPre).[10] The at-risk-of-poverty rate (defined as a percentage of persons living with less than 60% of median equalised disposable income) in Slovenia is 13.3% (or 268,000 people) compared to the EU average of 16.9%.

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[8] Eveline T. Feteris, *Fundamentals of Legal Argumentation*. Amsterdam 1999, p. 9.

[9] William B. Rouse, Nicoleta Serban, *Understanding and Managing the Complexity of Healthcare*. Cambridge 2014, p. 113.

[10] Social Assistance Payments Act [Zakon o socialno varstvenih prejemkih]. *Official Gazette of the Republic of Slovenia*, Nos. 61/10, 40/11, 14/13, 99/13, 90/15, 88/16, 31/18, 73/18 and 196/21 – ZDOsk.

For the beneficiaries of financial social welfare, mandatory health insurance is covered by their municipality of residence (Article 30 ZUPJS[11] in connection with the first paragraph of Article 28 ZSVarPre[12]), and voluntary health insurance is covered by the state (third paragraph of Article 24 ZZVZZ).[5] Since the low income population does not pay for healthcare services, it is impossible to improve their access to healthcare by lowering the cost of healthcare services.

The financial aspect of unmet needs of healthcare services could potentially be problematic only when using the Organisation for Economic Co-operation and Development (OECD) amount defining poverty, to the extent that it exceeds the national amount defining poverty. On the international level, the OECD has defined low income population as population where net disposable monthly income threshold of one-member household is lower than EUR 662 per month, of two-member household without children is lower than EUR 497 per person per month, and of four-member family (two adults and two children under 14) is lower than EUR 348 per person per month.[13]

4.2. Results of using the comparative method

In order to answer the question on whether or not there is unequal access to healthcare services for low income population in Slovenia, I have compared Slovenia with the average situation in the EU Member States and with three specific Member States (Croatia, Germany and Poland), also involved in the Humanities in the European Research Area (HERA) project called "Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe". The data used in the following figures is taken from the OECD and European Observatory on Health Systems and Policies, which annually publishes health reports for each Member State, in particular for Slovenia, Croatia, Poland and Germany.

In Croatia, in 2017 health expenditure per capita, at EUR 1,272, was among the lowest in the EU, where the average was EUR 2,884. Croatia earmarks 6.8% of its GDP to health, compared to the EU average of 9.8%. Nevertheless, the share of public expenditure, at 83%, is above the EU average. The benefit package is broad, but services require co-payments, for which many Croatians take out voluntary

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[11] Exercise of Rights from Public Funds Act [Zakon o uveljavljanju pravic iz javnih sredstev]. *Official Gazette of the Republic of Slovenia*, Nos. 62/10, 40/11, 40/12 – ZUJF, 57/12 – ZPCP-2D, 14/13, 56/13 – ZŠtip-1, 99/13, 14/15 – ZUUJFO, 57/15, 90/15, 38/16 – odl. US, 51/16 – odl. US, 88/16, 61/17 – ZUPŠ, 75/17, 77/18, 47/19 and 189/20 – ZFRO.

[12] Ibidem.

[13] Statistical Office of the Republic of Slovenia, *Income, poverty and social exclusion indicators*. Slovenia 2018. Available at: https://www.stat.si/StatWeb/en/News/Index/8175 (accessed 01.09.2020).

health insurance. Overall, out-of-pocket (OOP) payments, excluding voluntary health insurance, accounted for 10.5% of health expenditure in 2017, below the EU average of 15.8%.[14] In Poland, at EUR 1,507 per person, health spending is low compared to other countries in Europe and this gap does not appear to be closing. In 2017, Poland spent 6.5% of its GDP on health, compared to an average of 9.8% across the EU. Almost 70% of this spending came from public sources, a lower share than the average for the EU (79%). The rest is predominantly paid out of pocket by households, primarily for outpatient medicines.[15] In 2017 Germany spent EUR 4,300 per capita on healthcare (11.2% of GDP), about EUR 1,400 more than the EU average (EUR 2,884), and the highest level among the Member States. Germany also has some of the highest rates of beds, doctors and nurses per population in the EU. The share of spending on long-term care has increased significantly since 2000 and is expected to grow further due to the expanded benefit basket and population aging.[16]

I have looked into healthcare affordability from various perspectives, starting with the broadest states' perspective, followed by the narrower patients' perspective and concluding with the narrowest low income patients' perspective.

Figure 1 shows healthcare affordability from EU Member *States' perspective*. One can see that Slovenia is below the EU average regarding the percentage of Gross Domestic Product (GDP) per capita spending on healthcare. Thus, Slovenia as a Member State earmarks less public funds for the health of its citizens compared to other EU Member States.

Figure 2 shows the share of GDP spending on healthcare as a percentage specifically for Germany, Slovenia, Croatia and Poland.[17] In this regard, Slovenia is ranked second, after Germany and before Croatia.

The disparities among these specific Member States are even wider if one focuses on the purchasing power parity (PPP), which is defined as the rate of currency conversion that equalises the purchasing power of different currencies by eliminating the differences in price levels between the countries.

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[14] OECD, European Observatory on Health Systems and Policies, *Croatia: Country Health Profile 2019*. Paris, Brussels 2019. Available at: https://www.oecd-ilibrary.org/social-issues-migration-health/croatia-country-health-profile-2019_b63e8c9f-en (accessed 01.09.2020).

[15] Iidem, *Poland: Country Health Profile 2019*. Paris, Brussels 2019. Available at: https://www.oecd-ilibrary.org/social-issues-migration-health/poland-country-health-profile-2019_297e4b92-en (accessed 01.09.2020).

[16] Iidem, *Germany: Country Health Profile 2019*. Paris, Brussels 2019. Available at: https://www.oecd-ilibrary.org/social-issues-migration-health/germany-country-health-profile-2019_36e21650-en (accessed 01.09.2020).

[17] Iidem, *Germany*, op. cit.; iidem, *Slovenia*, op. cit.; iidem, *Croatia*, op. cit.; iidem, *Poland*, op. cit.

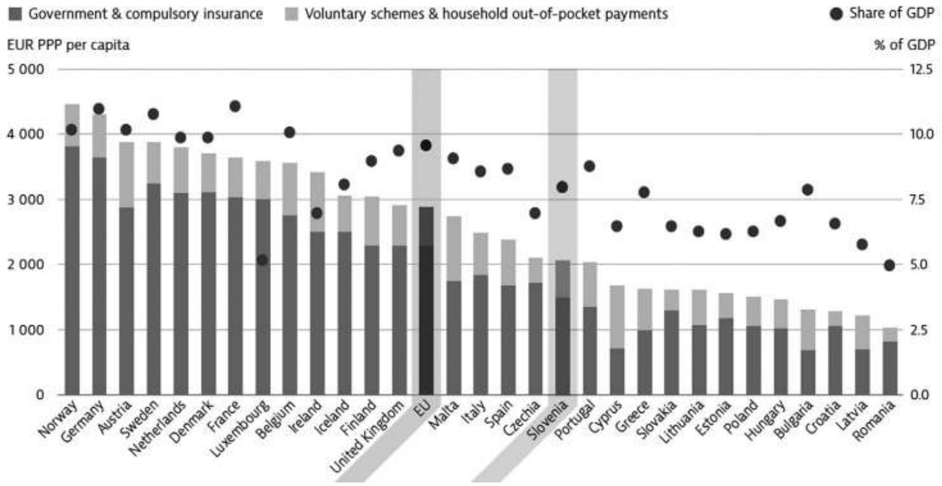

Figure 1. Share of GDP per capita spending on healthcare in EU Member States
Source: OECD Health Statistics 2019 (data refer to 2017).

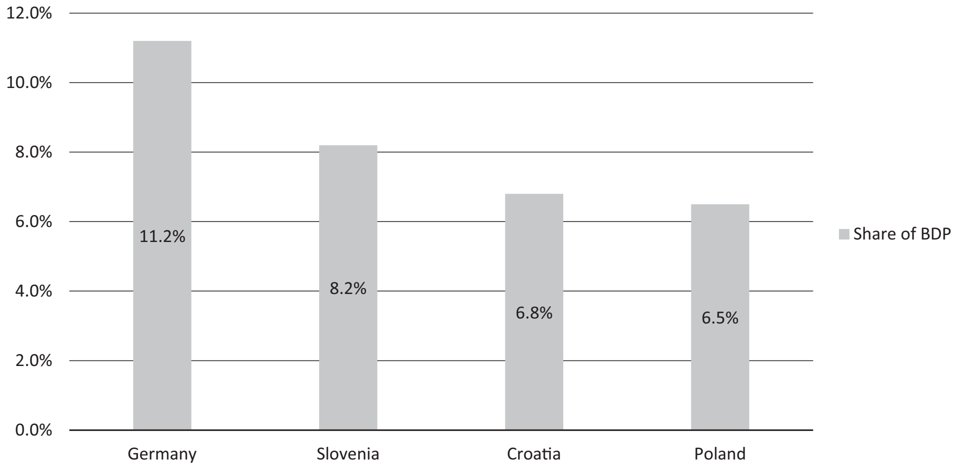

Figure 2. Share of GDP per capita spending on healthcare in Germany, Slovenia, Croatia and Poland

Source: own elaboration based on: OECD, European Observatory on Health Systems and Policies, *Germany: Country Health Profile 2019*. Paris, Brussels 2019; iidem, *Slovenia: Country Health Profile 2019*. Paris, Brussels 2019; iidem, *Croatia: Country Health Profile 2019*. Paris, Brussels 2019; iidem, *Poland: Country Health Profile 2019*. Paris, Brussels 2019.

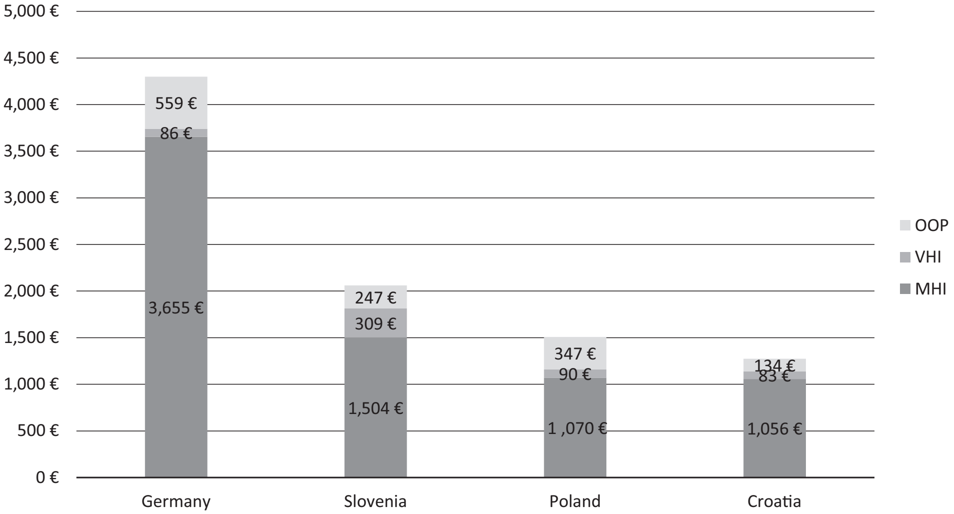

Figure 3. PPP spending on healthcare in Germany, Slovenia, Croatia and Poland

Source: own elaboration based on: OECD, European Observatory on Health Systems and Policies, *Germany: Country Health Profile 2019*, Brussels 2019. iidem, *Slovenia: Country Health Profile 2019*, Brussels 2019; iidem, *Croatia: Country Health Profile 2019*, Brussels 2019; iidem, *Poland: Country Health Profile 2019*, Brussels 2019.

Figure 3 shows the PPP spending on healthcare in euros. Again, the German share is more than twice as large as the Slovenian share. However, Slovenia has the largest share of VHI premiums (14.3%) in the whole EU.[18]

The second aspect focuses on healthcare affordability from *patients' perspective* by looking at the scope of catastrophic expenditure, defined as household out-of-pocket spending exceeding 40% of total household spending net of subsistence needs (i.e. food, housing and utilities).

The OOP spending is shown in Figures 1 and 4. In this regard, Slovenia has ranked below the EU average with 13.5% of funds being spent out of pocket.[19] Despite expenses for the VHI, it has one of the lowest rates of OOP spending on health in the EU. Therefore, Slovenian households are largely protected against catastrophic health expenditure, since only 2% of the population are affected. Considering that the Slovenian average of GDP spending on healthcare in general is below the EU average, this is surprising, since one would expect that the lack of public funds dedicated to healthcare would be compensated from private funds, thus falling above the EU average of 21%. This is for example the case

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[18] Iidem, *Slovenia*, op. cit.

[19] Ibidem.

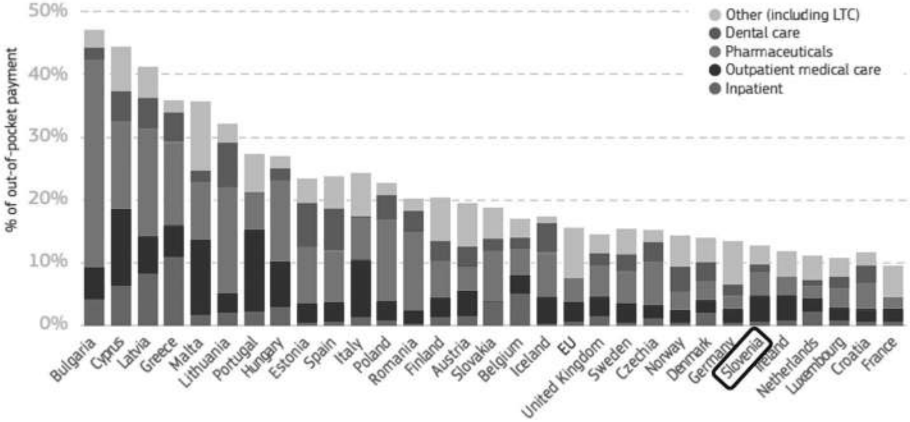

Figure 4. Share of OOP spending in EU Member States
Source: European Commission, *State of Health in the EU: Companion Report 2019*. Luxembourg 2019, p. 31.

with Poland,[20] where OOP spending accounts for 23%. The data is also shown for Croatia and Germany.[21]

The third aspect deals with healthcare affordability from *low income patients' perspective*, which is shown in broader Figure 5. Figure 5 shows healthcare accessibility and affordability particularities for Slovenia as a percentage of unmet medical needs.[22]

One can notice that Slovenia is the only EU Member State where unmet needs for high income groups are greater than those for low income groups. The grey dot (representing the high income population) is above the light grey dot (representing the low income population). The reason for this Slovenian particularity regarding healthcare affordability was explained in the chapter on linguistic methods and is related to the fact that the costs of healthcare services for low income population are fully covered by the municipalities and the state.

One can also notice the second Slovenian particularity regarding the availability of healthcare services. The grey dot (representing high income population) is very close together with the light grey dot (representing low income population), thus showing only minimal variation among income groups, while both being relatively distant from the X axis signifying zero unmet needs in healthcare. According to the OECD, the most likely reason for this

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[20] Iidem, *Poland*, op. cit.

[21] Iidem, *Croatia*, op. cit.; iidem, *Germany*, op. cit.

[22] European Commission, *State of Health in the EU: Companion Report 2019*. Luxembourg 2019. Available at: https://ec.europa.eu/health/sites/health/files/state/docs/2019_companion_en.pdf (accessed 01.09.2020).

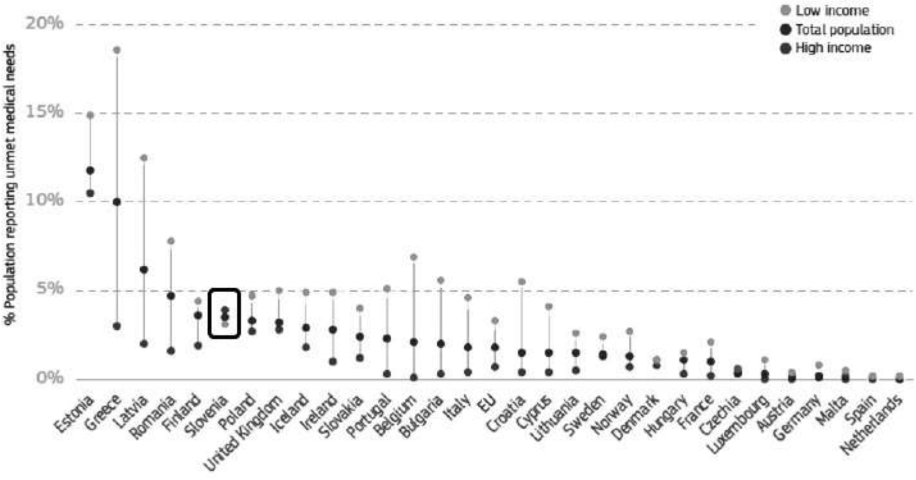

Figure 5. Unmet healthcare services needs for different income related population groups in EU Member States

Source: own elaboration based on European Commission, *State of Health in the EU: Companion Report 2019*. Luxembourg 2019.

particularity is that waiting times affect lower and higher incomes equitably in a system without many alternative private options.[23] The state owns almost the entire hospital capacity, most of the outpatient specialist care sector and the entire sector of tertiary care.[24] This practically means that, regardless of how much patients in Slovenia can afford to pay, they cannot buy any additional healthcare services from private healthcare providers on top of healthcare services provided by public healthcare providers, because there are no such services offered in the market. If such patients nevertheless require healthcare services, they need to travel to other EU Member States, in practice most often to the neighbouring Member State, Croatia.

4.3. Results of using the teleological method

The purpose of regulating the healthcare system in Slovenia is stated in Article 51 of the Slovenian Constitution.[25] In particular, the first paragraph guarantees everyone the right to healthcare under the conditions provided by law,

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[23] OECD, European Observatory on Health Systems and Policies, *Slovenia*, op. cit.

[24] Ibidem.

[25] Constitution of the Republic of Slovenia [Ustava Republike Slovenije]. *Official Gazette of the Republic of Slovenia*, Nos. 33/91-I, 42/97, 66/2000, 24/03, 69/04, 68/06, 47/13, and 75/16.

whereas the second paragraph guarantees everyone the rights to healthcare from public funds provided by law. The law is defined in Health Care and Health Insurance Act (ZZVZZ), which regulates the legal relationship between the HIIS and the insured persons. The ZZVZZ stipulates that the MHI guarantees insured persons reimbursement of health services costs in the percentage set by law (second paragraph of Article 13 ZZVZZ). The percentage coverage the ranges from 100% (for occupational diseases and injuries at work) to less than 70% (for injuries which are not work related).

When the demands for healthcare services required by the insured persons and guaranteed by the Constitution and the ZZVZZ are not met, one needs to look at the reasons for such a situation. The most teleologically efficient method to guarantee the constitutional and statutory rights related to healthcare is to confront the problems with access to healthcare where nationally there are the biggest gaps in comparison to the EU average.

Figure 6 shows the percentage of persons reporting unmet needs for medical examination or treatment, by main reason in 2018 (% of persons aged 16 and over) in Slovenia[26] compared to the rest of the EU Member States, in particular Croatia, Poland and Germany.[27]

Figure 7 shows a similar comparison, but with particular Member States (Germany, Croatia and Poland). One sees that practically the one and only obstacle to healthcare services for Slovenian patients is not the price of healthcare services (affordability of healthcare), but the waiting times to get healthcare services (availability of healthcare).

Combining Figure 3, showing how much insured persons pay for their healthcare services, (right-side Y axis) and Figure 7, showing how many of the insured persons actually receive access to healthcare services (left-side Y axis), gives us a cost-benefit analysis of the national healthcare systems of Slovenia, Croatia, Poland and Germany,[28] shown in Figure 8.

One can see that in Germany, Croatia and Poland the benefit of the healthcare system is more favourable to the insured persons and the patients. In Slovenia, on the other hand, the cost-benefit analysis gives a negative result, meaning that the insured persons pay more for their health insurance than they get out of the system when they require healthcare services in case of sickness or injury. One possible explanation could be that the current healthcare system in Slovenia focuses more on the interests of state run healthcare providers than on the interests of individual patients paying the MHI contributions. In the past,

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[26] OECD, European Observatory on Health Systems and Policies, *Slovenia*, op. cit.

[27] Iidem, *Croatia*, op. cit.; iidem, *Poland*, op. cit; iidem, *Germany*, op. cit.

[28] Iidem, *Slovenia*, op. cit.; iidem, *Croatia*, op. cit.; iidem, *Poland*, op. cit.; iidem, *Germany*, op. cit.

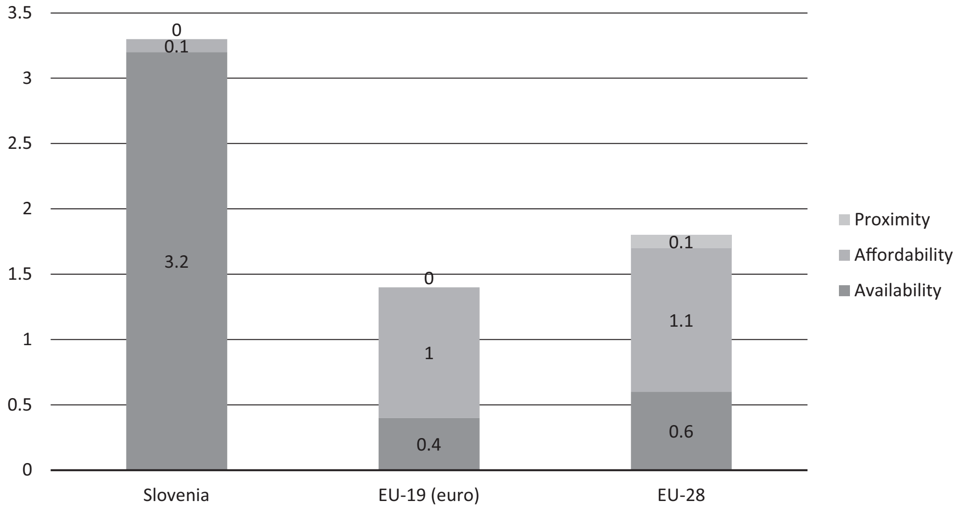

Figure 6. Share of persons reporting unmet healthcare services needs by main reason in Slovenia, the Eurozone and in the whole EU

Source: own elaboration.

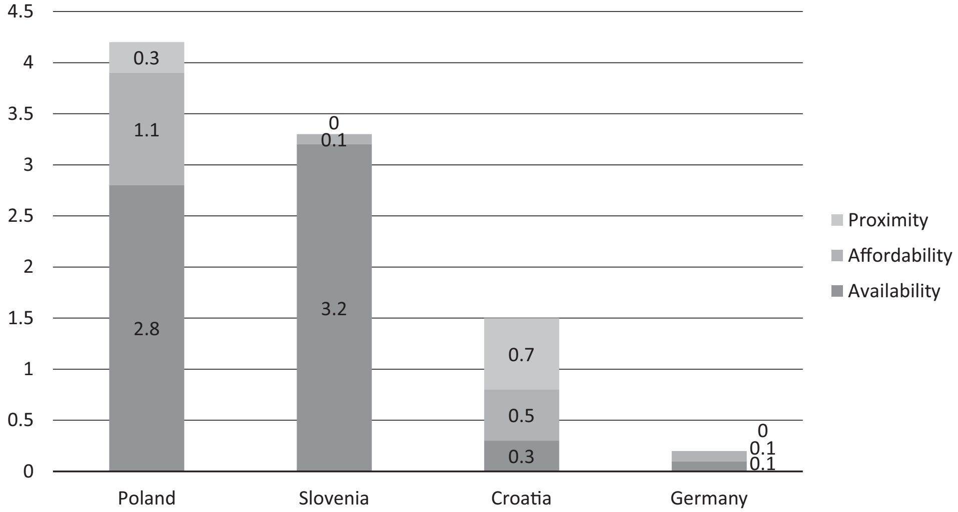

Figure 7. Share of persons reporting unmet healthcare services needs by main reason in Poland, Slovenia, Croatia and Germany

Source: own elaboration.

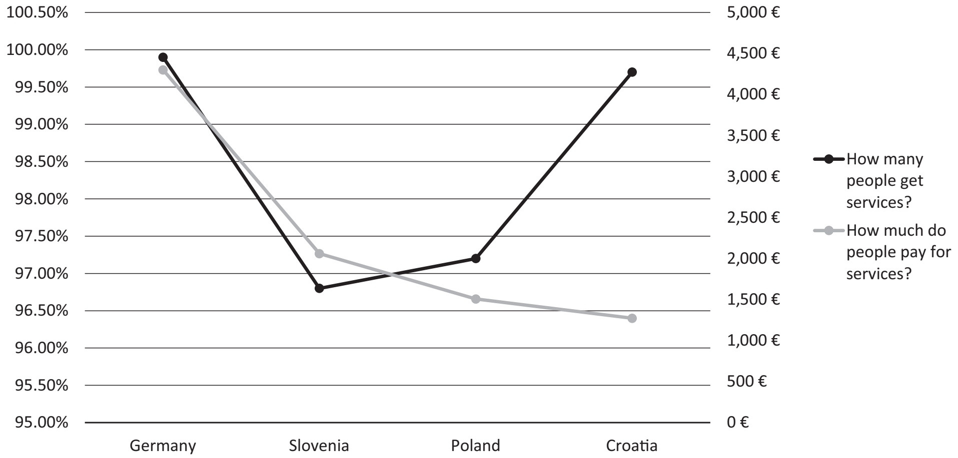

Figure 8. Cost-benefit analysis of healthcare systems in Germany, Slovenia, Poland and Croatia

Source: own elaboration.

the National Assembly has for example passed an Act Determining Intervention Measures to Ensure the Financial Stability of Public Healthcare Institutions Established by the Republic of Slovenia (ZIUFSZZ).[29] The teleological method thus answers the question whether the purpose of the whole healthcare system is set up in a way which helps to take care of the users of healthcare services (patients) or taking care of the providers of healthcare services (hospitals).

4.4. Results of using the historical method

The historical method refers to the comparison of the Slovenian and the Croatian healthcare systems, both of which come from the same federal healthcare system of former Yugoslavia. Over the years, the two healthcare systems developed into what shows a ten times higher availability of healthcare in Croatia compared to the availability of healthcare in Slovenia. One of the possible reasons for such a significant difference could stem from the differences defining the public network of healthcare providers, in particular the degree of network flexibility. In Slovenia, the national health insurance provider only finances healthcare services offered by the healthcare providers that are established or

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[29] Act Determining Intervention Measures to Ensure the Financial Stability of Public Healthcare Institutions Established by the Republic of Slovenia [Zakon o interventnih ukrepih za zagotovitev finančne stabilnosti javnih zdravstvenih zavodov, katerih ustanovitelj je Republika Slovenija]. *Official Gazette of the Republic of Slovenia*, Nos. 54/17 and 16/20 – ORZIUFSZZ7.

certified by the state (first paragraph of Article 64 ZZVZZ),[30] but not healthcare services offered by private healthcare providers. In contrast, the Croatian national health insurance provider (The Health Insurance Institute) finances all healthcare services provided either by public or private healthcare providers (first paragraph of Article 88 ZoZo).[31] The second important difference between the two healthcare systems is the possibility of the national health insurance provider to transfer the risk of proper performance of healthcare services to healthcare providers. In Slovenia, the health insurance provider cannot terminate the contract with healthcare providers if the provider does not comply with the contractual duties, but can only notify the Ministry of Health (second paragraph of Article 77 ZZVZZ).[5] In turn, the Croatian health insurance provider has the power to terminate a financing contact with the healthcare provider which does not comply with the contractual duties (fourth paragraph of Article 94 ZoZo).[32]

4.5. Results of using the systematic method

The systematic method is focused on the whole system of healthcare stakeholders, consisting of insured persons or patients, health insurance provider, healthcare providers and healthcare workers (i.e. physicians, nurses and health technicians). The purpose of the healthcare system is to transform the MHI contributions collected from the insured persons into healthcare services needed by the same insured persons when they become ill or injured by using all the available resources of healthcare system stakeholders. The process is shown in Figure 9.

On the input side of the healthcare system, one can talk about the affordability of healthcare services, where the most significant question is the amount of MHI contributions. On the output side of the healthcare system, one can talk about the availability of healthcare services, where the most important question is the number of healthcare services provided. Since the whole healthcare system is interdependent, the legislator has to ensure that patients needing healthcare services get the benefit from all the available and interconnected healthcare resources.

4.6. Overall result findings

The majority of the legal methods used show that the suboptimal access to healthcare in Slovenia is not caused by the high price of the offered healthcare services, but by the waiting times for a healthcare service. This implies that

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[30] Healthcare and Health Insurance Act, op. cit.

[31] Health Insurance Act [Zakon o obveznom zdravstvenom osiguranju] *Official Gazette of the Republic of Croatia "Narodne novine"*, No. 71-05-03/1-08-2.

[32] Ibidem.

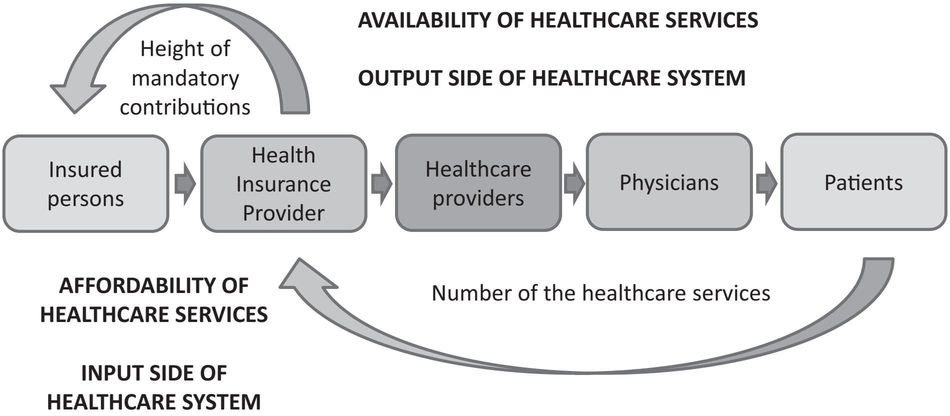

Figure 9. Healthcare system stakeholders and their relationships
Source: own elaboration.

the input side (i.e. the distribution of payments) of the Slovenian healthcare system causes only minor problems, and that the major problem of the healthcare system is its output side (i.e. the number of provided healthcare services). In addition, the used legal methods show that the former healthcare reform could not improve overall access to healthcare, since it only addresses 0.1% of 3.3% of current total unmet needs of healthcare services.

5. Discussion

Based on the foregoing analysis, I try to find the ways of how to eliminate the existing barriers which diminish the number of healthcare services without simultaneously jeopardising the financial sustainability of the existing healthcare system. That is, how to improve healthcare availability for the total population, not just the low income population, by addressing obstacles that currently hinder an efficient transformation of paid MHI contributions into received healthcare services.

5.1. Which are the most significant obstacles hindering healthcare availability?

With regard to obstacles between the health insurance provider and healthcare providers, the most significant obstacle in the Slovenian legal system could be the statutory requirement that healthcare providers are either established by the state or get certified by the state if they were established by a private entity. Due to the differences explained in the chapter on historical method and shown in Figure 7, Croatia (0.3%) has therefore ten times higher healthcare availability than Slovenia (3.2%).

With regard to obstacles between healthcare providers and physicians, the most significant obstacle could be the statutory arrangement that healthcare providers can pay healthcare workers, including physicians, only a fixed, hourly based salary. In Slovenia, healthcare workers are considered public workers whose salary and potential reward for an increased workload is based solely on the number of working hours, while completely disregarding the number of healthcare services performed (Article 21 ZSPJS).[33] An additional problem with the dysfunctional reward mechanisms is posed by the fact that the reward for increased workload can only be calculated if the healthcare provider is familiar with the regular workload of a particular healthcare specialty for a particular healthcare worker. However, since working standards in the healthcare sector are not established, an increased workload as the requirement for a reward cannot be established either. Supposedly, that is the reason why a special government project for reducing healthcare waiting times, promoted in 2017, had only a 17% completion (second paragraph of Article 22d ZSPJS).[34]

With regard to obstacles between physicians and patients, the most significant obstacle could be the fact that general practitioners (GPs) are overloaded with assigned patients. Since it would be too time consuming to treat them by themselves, they refer them to specialist care instead. As the OECD found out, a rise in the number of patients with chronic conditions is creating an increased workload for the already low number of GPs, which in turn results in more specialist referrals and longer waiting times.[35] Figure 10 shows the average number of nurses and the average number of doctors in EU Member States.[36] The Slovenian average is 3.1 per 1,000 population, and the EU average is 3.6 per 1,000 population.

However, if one looks at the workload of GPs in independent practice compared to the workload of GPs employed by public healthcare providers, one can notice a significant difference in the number of patients they treat (shown in Figure 11). While independent GPs treat just as many patients to reach a required level for receiving full public funding from the national health insurance provider, the number of patients treated by employed GPs is lower than

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[33] Public Sector Salary System Act [Zakon o sistemu plač v javnem sektorju, ZSPJS]. *Official Gazette of the Republic of Slovenia*, Nos. 108/09 – uradno prečiščeno besedilo, 13/10, 59/10, 85/10, 107/10, 35/11 – ORZSPJS49a, 27/12 – odl. US, 40/12 – ZUJF, 46/13, 25/14 – ZFU, 50/14, 95/14 – ZUPPJS15, 82/15, 23/17 – ZDOdv, 67/17 and 84/18).

[34] Cf. Report on the implementation of a special government project to shorten waiting times and increase the quality of healthcare – Proposal for consideration [Poročilo o izvajanju Posebnega vladnega projekta za skrajševanje čakalnih dob in povečanje kakovosti zdravstvene obravnave – predlog za obravnavo], No. 170-15/2017/1307. Ljubljana: Ministry of Health of Republic of Slovenia, 2018.

[35] OECD, European Observatory on Health Systems and Policies, *Slovenia*, op. cit.

[36] Ibidem.

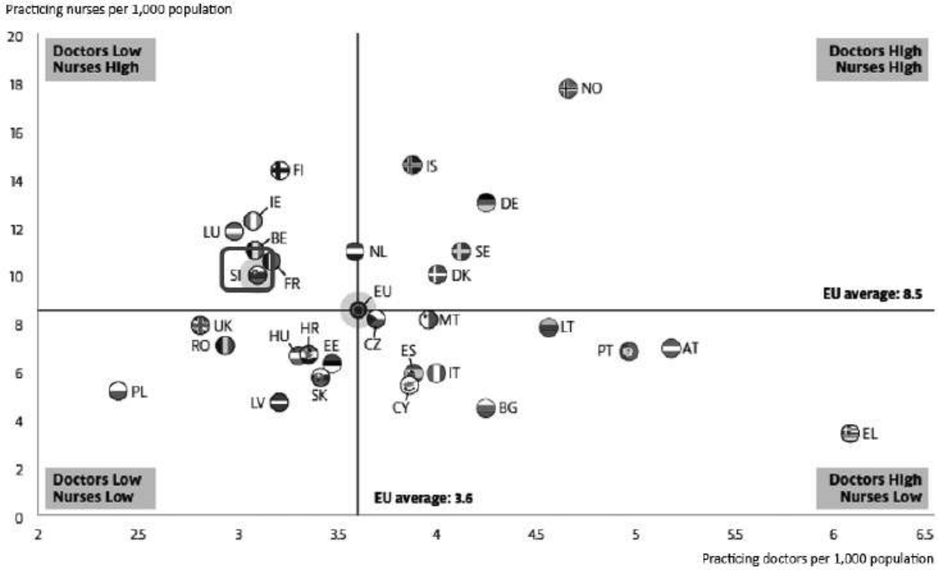

Figure 10. Average number of nurses and average number of doctors in EU Member States

Source: OECD, European Observatory on Health Systems and Policies, *Slovenia: Country Health Profile 2019*, Brussels 2019.

the required standard prescribed by the national health insurance provider. The most probable reason for this statistically significant difference in their behaviour is that healthcare workers' performance can only be efficiently stimulated if it is supported by appropriate financial incentives. In comparison, the salary systems where the amount of the salary remains unrelated to the number of patients they treat, in time results in a downward spiral, where the health insurance provider has to adjust the required workload to their fixed salary, as seen in Figure 11.

5.2. Which would be the most significant changes for improving healthcare availability?

The most crucial change concerning the relationship between patients and physicians which could potentially improve healthcare availability in Slovenia could be to change the focus of the national healthcare system. Instead of concentrating on healthcare providers and guaranteeing a constant flow of patients requiring healthcare services for them, one could concentrate on patients themselves and allow them the freedom to choose their physician and healthcare provider, whom they would trust with their treatment. The right to freely choose a physician and a healthcare provider is already established in the ZZVZZ,

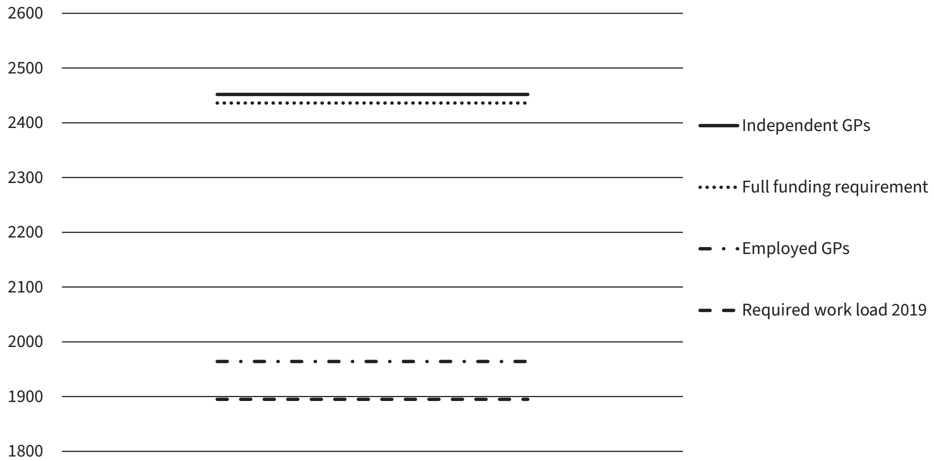

Figure 11. Workload of GPs in Slovenia depending on their working status presented in numbers of assigned patients, weighted by age

Source: Data from Health Insurance Institute of Slovenia.

and the right to the reimbursement of costs of the healthcare services is already established in the Patients' Rights Act (ZPacP).[37] However, these statutory rights are not implemented in practice because their scope is restricted by the implementing regulations of the national health insurance provider (first paragraph of Article 158 and Article 254 POZZ).[38] One part of Article 254 POZZ has already been repealed by the Constitutional Court in the case Mihelič and others back in 1998.[39] In that landmark case, the Court defined the right to freely choose a physician and a healthcare provider by connecting the freedom to choose the physician with the duty to pay MHI contributions. It ruled that the National Health Insurance provider is obliged to allow the free choice of a physician and a healthcare provider at all levels of healthcare (outpatient or inpatient care), since such a right arises from the contributions paid for mandatory health insurance. Consequently, the Court found the contested provision in the Rules on compulsory health insurance, requiring the insured person to pay the full price of the healthcare service if the service is provided by a private healthcare provider,

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[37] Patients' Rights Act [Zakon o pacientovih pravicah]. *Official Gazette of the Republic of Slovenia*, Nos. 15/08, 55/17 and 177/20.

[38] Rules amending the Rules on compulsory health insurance [Spremembe in dopolnitve Pravil obveznega zdravstvenega zavarovanja]. *Official Gazette of the Republic of Slovenia*, No. 183/21.

[39] Case of Mihelič and others, Constitutional Court, judgment No. U-I-125/97 of 24 June 1998. Available at: http://odlocitve.us-rs.si/sl/odlocitev/US19025?q=absurdna+zzvzz+obveznega+zavarovanja (accessed 01.09.2020).

on top of the requirement to pay MHI contributions, absurd, and in consequence repealed the provision. However, it took the national health insurance provider 20 years to enforce the judgment with changing their instructions for healthcare providers.[40] The second crucial change concerning the relationship between physicians and healthcare providers could be to upgrade the salary system of public workers with the possibility to award public workers the variable part of their salary on top of their fixed salary, thus rewarding the efficiency and intensity of their performance. Since a variable part of the salary does not require a set of working standards and norms, it would presumably be more widely applicable than the former government project aimed at reducing waiting times for healthcare services.[41] The third important change concerning the relationship between healthcare providers and the national health insurance provider could be to change the criteria that currently define the public network of healthcare providers in Slovenia. According to the established case law of the European Court of Justice, the established Slovenian criteria for public financing of healthcare providers (explained in more detail above) could presumably be declared as a state aid incompatible with the internal EU market (first paragraph of Article 107 TFEU).[42] It supposedly fulfils all four conditions required by the settled case law of the ECJ. First, the law requires the state as a founder of the healthcare institution to financially intervene when it finds itself in a financial difficulty (second paragraph of Article 48 and second paragraph of Article 49 ZZ).[43] Second, this financial intervention could be liable to affect trade between the Member States since it strengthens the position of public healthcare providers as compared with that of private healthcare providers competing in trade between the Member States, while it is not necessary for the beneficiary healthcare provider to be directly involved in trade between the Member States. Third, financial intervention by the state confers a selective advantage only on those healthcare providers whose founder is the state. Fourth, financial intervention threatens to distort competition (ECJ judgment in the case Azienda Napoletana

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[40] Instructions for exercising the right to healthcare services with a referral, General Director of Health Insurance Institute, No. 0072-18/2018-DI/1 of 17 October 2018. Available at: https://www.zzzs.si/ZZZS/info/egradiva.nsf/o/38FF11568D0E77C7C12577FB00426E00 (accessed 01.09.2020).

[41] Cf. Report on the implementation..., op. cit.

[42] Treaty on the Functioning of the European Union (TFEU). *Official Journal of the European Union*, C 326, 26.10.2012. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:12012E/TXT&from=EN (accessed 01.09.2020).

[43] Institutes Act [Zakon o zavodih]. *Official Gazette of the Republic of Slovenia*, Nos. 12/91, 8/96, 36/00 – ZPDZC and 127/06 – ZJZP.

Mobilità, C-659/17, paragraphs 20, 29, 30 and 31).[44] However, compensation for services provided in order to discharge public service obligations does not constitute state aid if the parameters on the basis of which the compensation is calculated are established in advance in an objective and transparent manner (ECJ judgment in case of Altmark Trans, C-280/00, paragraphs 88 to 93).[45]

Based on the stated criteria, one could argue that the scope of the constitutional power of the state to regulate and operate the MHI through the national health insurance provider is only compatible with the EU internal market if the selection of healthcare providers financed by that health insurance provider is based on quality, cost and scale of their healthcare services, but not on the state's power to selectively finance healthcare providers by exercising its founding rights.

6. Conclusion

I conclude that abandoning the VHI and substituting it with the MHI would only moderately improve financial access to healthcare services for the low income population, but would not improve timely access to healthcare for all the population groups regardless of their income. I propose that the new healthcare reform in Slovenia should not concentrate on how to achieve equal access to healthcare services, but should shift its focus on how to improve access to healthcare services. Possible ways of legally addressing the most significant obstacles in relationships among the healthcare system stakeholders were presented in the discussion section of the paper.

Furthermore, one could strengthen access to healthcare or expedite the health system reform by acquiring financial support from the European Structural and Investment (ESI) Funds that could become an important source of external funding for the health system. For the 2014–2020 programmes, over EUR 8 billion was spent on health projects, which means an average project budget of approximately EUR 1.2 million. For over half of the projects (57%), the main funding source was the ESI Fund. Poland and Germany were among the Member States with the largest numbers of health-related projects. For access to healthcare projects, Croatia in particular received EUR 216.7 million, Poland received EUR 12.8 million and Germany received EUR 3.6 million out of a total of EUR 1.3 billion for all the Member States. For the health system

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[44] Case of Azienda Napoletana Mobilità, European Court of Justice, judgment of 29 July 2019 No. C-659/17, ECLI:EU:C:2019:633. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:62017CJ0659 (accessed 01.09.2020).

[45] Case of Altmark Trans in Regierungspräsidium Magdeburg, European Court of Justice, judgment of 24 July 2003 No. C-280/00, EU:C:2003:415. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:62000CJ0280 (accessed 01.09.2020).

reform projects in particular, Poland received EUR 530.1 million out of a total of EUR 1.6 billion for all the Member States. Slovenia, on the other end, received EUR 0.060 million for access to healthcare projects and zero EUR for health system reform projects.[46]

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[46] European Commission, ESI Funds for Health, *Investing for a healthy and inclusive EU. Final Report 2019*. Avalable at: http://www.esifundsforhealth.eu/sites/default/files/2019-03/Final%20Report%20ESI%20Funds%20for%20Health_2.pdf. (accessed 01.09.2020).

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Jasna Murgel

Legal remedies for the victims of discrimination based on ethnic origin in Slovene and international law

1. Introduction

One of the general principles in democratic societies is that the legal system should ensure compliance with the principle of equal treatment. This goal is to be achieved by regulating the rules of equal treatment, sanctions for breaching them, and mechanisms allowing the alleged victims of unequal treatment to use effective legal remedies for eliminating the violation and its consequences.

This contribution addresses a narrow segment of regulating equal treatment, namely the remedies available to victims of discrimination according to international and Slovene law if it occurs in the field of healthcare and is based on ethnic origin.

2. International law

The system of human rights that has emerged after the Second World War within the United Nations Organisation is based on the principle of prohibition of discrimination on any grounds and of the protection of human rights.

The International Covenant on Civil and Political Rights (CCPR)[1] is based on the ideal of free human beings enjoying civil and political freedoms and freedom from fear. This can only be achieved if conditions are created whereby everyone may enjoy his or her civil and political rights, as well as economic, social and cultural rights. The states parties to the CCPR are bound "to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognised in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (Article 2).

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[1] International Covenant on Civil and Political Rights. United Nations General Assembly. Available at: https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx (accessed 30.05.2020).

According to the International Covenant on Economic, Social and Cultural Rights (CESCR),[2] its parties undertake to take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of their available resources, with a view to achieving progressively a full realisation of the rights recognised by the Covenant by all appropriate means, including particularly the adoption of legislative measures. The states-parties must guarantee that the rights enunciated in the Covenant will be exercised without discrimination of any kind (Article 2).

One of the most important international treaties prohibiting discrimination is the International Convention on the Elimination of All Forms of Racial Discrimination (CERD).[3] It regulates the most general prohibition of discrimination. Racial discrimination is defined as "any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life" (Article 1, paragraph 1). Under the CERD, the states-parties are obliged "to assure to everyone within their jurisdiction effective protection and remedies, through the competent national tribunals and other state institutions, against any acts of racial discrimination which violate his human rights and fundamental freedoms contrary to this Convention, as well as the right to seek from such tribunals just and adequate reparation or satisfaction for any damage suffered as a result of such discrimination" (Article 6). The states-parties must "prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization"; they must "encourage, where appropriate, integrationist multiracial organisations and movements and other means of eliminating barriers between races, and discourage anything which tends to strengthen racial division" (Article 2).

The International Convention on the Rights of the Child (CRC)[4] also prohibits discrimination based on ethnic origin. Its parties must "respect and ensure the rights set forth in the Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal

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[2] International Covenant on Economic, Social and Cultural Rights. United Nations General Assembly. Available at: https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx (accessed 25.05.2020).

[3] International Convention on the Elimination of All Forms of Racial Discrimination. United Nations General Assembly. Available at: https://www.ohchr.org/en/professionalinterest/pages/cerd.aspx (accessed 29.05.2020).

[4] The International Convention on the Rights of the Child. United Nations General Assembly. Available at: https://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 29.04.2020).

guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status" (Article 2).

2.1. Complaint procedures for individuals

The ability of individuals to complain about the violation of their rights in an international arena brings real meaning to the rights enshrined in the human rights treaties. The above-mentioned international treaties or their protocols regulate a system for monitoring their implementation by treaty bodies, committees composed of independent experts.[5] Any individual who claims that her or his rights under the mentioned treaties have been violated by a state-party to that treaty may bring a communication before the relevant committee, provided that the state has recognised the competence of the committee to receive such complaints and that domestic remedies have been exhausted:[6]

- the Human Rights Committee[7] may consider individual communications alleging violations of the rights set forth in the CCPR by the states-parties to the First Optional Protocol to the Covenant;
- the Committee on the Elimination of Racial Discrimination[8] may consider individual petitions alleging violations of CERD by States parties who have made the necessary declaration under article 14 of the Convention;
- the Committee on Economic, Social and Cultural Rights may consider individual communications alleging violations of the CESCR by the states-parties to the Optional Protocol to the Covenant, and
- the Committee on the Rights of the Child may consider individual communications alleging violations of the ICRC or its two first Optional Protocols on the sale of children, child prostitution and child pornography, and on the involvement of children in armed conflict by the state-parties to the Third Optional Protocol in the communications procedure,
- the Committee on the Elimination of Discrimination against Women (CEDAW) is a body of independent experts that monitors the implementation of the Convention on the Elimination of All Forms of Discrimination against Women.[9]

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[5] Louis B. Sohn, "Human rights: Their implementation and supervision by the United Nations". In: Theodor Meron (ed.), *Human Rights in International Law*. Oxford 1984, pp. 373–384.

[6] United Nations, Office of the High Commissioner for Human Rights, *Monitoring the Core International Human Rights Treaties*. Available at: https://www.ohchr.org/EN/HRBodies/Pages/WhatTBDo.aspx (accessed 21.05.2020).

[7] Torkel Opsahl, "The Human Rights Committee". In: Phillip Alston (ed.), *The United Nations and Human Rights. Critical Appraisal*. Oxford 1992, p. 369.

[8] Karl Josef Partsch, "The Committee on the Elimination of Racial Discrimination". In: Alston (ed.), *The United Nations*..., op. cit., pp. 339–368.

[9] Opsahl, "The Human Rights...," op. cit., p. 369.

3. European Convention and the Court of Human Rights (ECHR)

The most effective mechanism of monitoring implementation of the international treaty on human rights is regulated by the ECHR.[10] The ECHR has a significantly broader scope than the EU non-discrimination directives, both in terms of substantive rights and how they are interpreted for the purposes of applying Article 14 of the ECHR. While European anti-discrimination law forbids both direct and indirect discrimination, it does so only in limited circumstances.[11]

The ECHR regulates the procedure for individual or state applications alleging violations of the civil and political rights set out in the Convention and its protocols, especially Protocol No. 12. The system of protection of fundamental rights and freedoms established by the ECHR is based on the principle of subsidiarity. The task of ensuring the application of the Convention falls primarily to the states-parties to the Convention; the European Court on Human Rights (ECHR) should intervene only where states have failed in their obligations.[12] Protocol No. 12 to the ECHR provides for a general prohibition of discrimination. The current non-discrimination provision of the ECHR is of a limited kind because it only prohibits discrimination in the enjoyment of one or the other rights guaranteed by the Convention. According to Article 14, "the enjoyment of the rights and freedoms set forth in the Convention must be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status". Protocol No. 12 extends this prohibition to any enjoyment of any right set forth by law.

The parties to a case must abide by the judgments of the ECHR and take all necessary measures to comply with them. The Committee of Ministers of the Council of Europe supervises the execution of judgments. The Secretary General may request the parties to provide explanations on the manner in which their domestic law ensures the effective implementation of the ECHR (Article 46). Failure to enforce a judgment delivered by the ECHR finding a violation of the ECHR may amount to a new violation of the Convention.[13]

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[10] European Convention on Human Rights. European Court of Human Rights–Council of Europe. Available at: https://www.echr.coe.int/Documents/Convention_ENG.pdf (accessed 28.04.2020).

[11] European Union Agency for Fundamental Rights, Council of Europe, *Handbook on European non-discrimination law. 2018 edition*. Luxembourg 2018. Available at: https://fra.europa.eu/en/publication/2018/handbook-european-law-non-discrimination (accessed 02.05.2020), p. 112.

[12] European Court of Human Rights, *Practical Guide on Admissibility Criteria, updated on 30 April 2019*, p. 7. Available at: https://www.echr.coe.int/Documents/Admissibility_guide_ENG.pdf (accessed 12.05.2020).

[13] European Union Agency for Fundamental Rights, Council of Europe, *Handbook*..., op. cit., pp. 251–252.

The Court may receive applications from any person, non-governmental organisation or group of individuals claiming to be the victim of a violation by one of the states-parties of the rights set forth in the ECHR or the Protocols thereto (Article 34). This provision, which guarantees the right of individual application, gives individuals a genuine right to take legal action at international level. It is also one of the fundamental guarantees of the effectiveness of the Convention system – one of the "key components of the machinery" for the protection of human rights.[14]

In order to lodge an application successfully, one must be informed about the admissibility rules. The ECHR explicitly lays down the conditions for lodging an individual application (Article 35), and certain conditions result from its content or other rules of international law. The basic principle is that the ECHR is competent for an individual application only if the alleged infringement has been committed by the state, i.e. its authorities in the exercise of its own functions. Infringements caused by natural or legal persons, where they do not appear on behalf of the state, do not fall within its jurisdiction.[15]

The obligation to exhaust domestic remedies forms part of customary international law, recognised as such in the case-law of the International Court of Justice. The applicant must use the remedies available in accordance with the internal legislation of the given state. It is not enough to turn to ordinary courts. The applicant must also take advantage of other remedies before ordinary, specialised, administrative and constitutional courts. However, it is not necessary to use exceptional remedies that would be available to him or her as a privilege. Nor is it necessary for the applicant to ask for acts of mercy or for social services.[16]

The ECHR may only deal with the matter within a period of six months from the date on which the final decision was taken (Article 35, paragraph 1). The primary purpose of the six-month rule is to maintain legal certainty by ensuring that cases raising issues under the Convention are examined within a reasonable time, and to prevent the authorities and other persons concerned from being kept in a state of uncertainty for a long period of time.[17]

The matter submitted must not be substantially the same as the matter that has already been examined by the ECHR or has already been submitted to another procedure of international investigation or settlement and contains no relevant

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[14] Cf. case of Mamatkulov and Askarov v. Turkey, European Court of Human Rights, Applications nos. 46827/99 and 46951/99, paragraphs 100 and 122; European Court of Human Rights, *Practical Guide on Admissibility Criteria*, p. 9. Available at: https://www.echr.coe.int/Documents/Admissibility_guide_ENG.pdf (accessed 15.05.2020).

[15] Jack Donnelly, *The Concept of Human Rights*. London, Sydney 1985.

[16] J.E.S. Fawcett, *The Application of The European Convention on Human Rights*. Oxford 1987, pp. 356–362.

[17] European Court of Human Rights, *Practical Guide...*, op. cit., p. 30.

new information. New facts are only those that were not known at the time when the previous request for consideration had been filed, or which arose after the case had already been decided.[18] The ECHR declares inadmissible any application which is not in compliance with the provisions of the Convention or its protocols, is manifestly unfounded or constitutes an abuse of the right to appeal.[19]

The ECHR does not deal with anonymous individual applications (Article 35, paragraph 2).[20] It also declares inadmissible any individual application submitted if it considers that the application is an abuse of the right of individual application (Article 35, paragraph 3). According to the ECHR practical guide on admissibilty criteria, "any conduct of an applicant that is manifestly contrary to the purpose of the right of individual application as provided for in the Convention and impedes the proper functioning of the ECHR or the proper conduct of the proceedings before it constitutes an abuse of the right of application".[21] The individual application must not be incompatible with the provisions of the Convention and the protocols thereto (Article 35, paragraph 3).

3.1. International treaty bodies and the ECHR jurisprudence

3.1.1. Treaty bodies

Alyne da Silva Pimental Teixeira,[22] a Brazilian national of African descent who was six months pregnant when she began experiencing nausea and severe abdominal pains, filed a complaint with the CEDAW. She sought aid from a private health centre, but received terrible care; her condition worsened, and she requested an ambulance from a public hospital. The request was turned down. Alyne did not receive the necessary emergency healthcare because her family could not afford the price of a private ambulance. She then suffered a haemorrhage and died in hospital. Alyne's mother filed a complaint with the CEDAW.

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[18] Ibidem, pp. 60–62.

[19] Donna Gomien, *Kratek vodič po Evropski konvenciji o človekovih pravicah in temeljnih svoboščinah*. Ljubljana 1995, p. 151.

[20] Donna Gomien, David Harris, Leo Zwaak, *Law and Practice of the European Convention on Human Rights and the European Social Charter*. Strasbourg 1996, p. 61.

[21] European Court of Human Rights, *Practical Guide...*, op. cit., p. 41.

[22] Views of the Committee on the Elimination of Discrimination against Women under article 7, paragraph 3, of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women. Committee on the Elimination of Discrimination against Women, CEDAW/C/49/D/17/2008. Available at: https://www2.ohchr.org/english/law/docs/CEDAW-C-49-D-17-2008.pdf (accessed 30.04.2020); European Union Agency for Fundamental Rights, *Inequalities and Multiple Discrimination in Access to and Quality of Healthcare*. Luxembourg 2013, p. 23.

Alyne had been discriminated against not just because of her sex, but also because of her status as a woman of African origin and her socioeconomic background, according to the Committee. This was the first case in which the CEDAW found numerous grounds of discrimination in healthcare by a state-party failing to meet its obligations under Articles 2 and 12 of the CEDAW to provide access to healthcare.

The CEDAW Committee voiced its concern about non-consensual sterilisations, particularly of Roma women and women with mental disabilities, in its concluding observations on the Czech Republic's periodic state report.

In its concluding observations from 2016, the CEDAW recommends the state-party expeditiously to undertake the legislative amendments necessary to ensure that migrant women and girls residing in the state-party have the same access to public health insurance as nationals.[23]

The Committee on Economic, Social and Cultural Rights has also expressed concerns over unequal access to healthcare for all in the United Kingdom, claiming that health inequalities have expanded among social classes, particularly in terms of healthcare goods, facilities, and services.[24]

3.1.2. The European Court of Human Rights

The ECHR dealt with a number of cases involving Roma women's forced sterilisation. Three Roma women from Slovakia, two of whom were minors at the time of the incident, say that they were segregated in so-called "gypsy rooms" and sterilised without their knowledge or consent while undergoing caesarean sections. The applicants claimed violations of Articles 3, 8, and 12 of the ECHR, as well as that their sterilisations were based on sex, race, colour, national minority membership and ethnicity, in violation of Article 14 in connection with Articles 3, 8, and 12 of the ECHR. These cases were later dropped by the court due to a settlement between the parties, which may have presented the court with an opportunity to explain how Article 14 applied to the use of medical treatments.[25]

The European Court of Human Rights ruled in favour of a 20-year-old Roma woman who was sterilised in a public hospital without her informed consent

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[23] Concluding observations on the sixth periodic report of the Czech Republic. Committee on the Elimination of Discrimination against Women, CEDAW/C/CZE/CO/6, 14 March 2016.

[24] Consideration of reports submitted by States parties under articles 16 and 17 of the Covenant: Concluding observations of the Committee on Economic, Social and Cultural Rights United Kingdom of Great Britain and Northern Ireland, the Crown Dependencies and the Overseas Dependent Territories. Committee on Economic, Social and Cultural Rights, E/C.12/GBR/CO/5, 12 June 2009.

[25] European Union Agency for Fundamental Rights, *Inequalities and multiple*…, op. cit., p. 25.

in the case of V.C. v. Slovakia in 2011.[26] The ECHR's first decision in a case involving a forcibly sterilised Roma woman found violations of Articles 3 and 8.

Similarly, in June 2012, the ECHR delivered the judgment on N. B. v. Slovakia,[27] a case on forced sterilisation of a Roma woman at a public hospital and her subsequent failure to obtain redress. Even though the applicant complained that she was discriminated against on more than one ground (race/ethnic origin and sex), the ECHR made no explicit reference in its judgment to discrimination or multiple discrimination; however, it stated that "the practice of sterilisation of women without their prior informed consent affected vulnerable individuals from various ethnic groups". It ruled that Articles 3 (prohibition of torture), 7 (no punishment without law) and 9 (freedom of thought, conscience and religion) of the ECHR had been violated.[28]

The ECHR had ruled on several other cases concerning Roma women who complained that they had been sterilised, namely the cases I.G., M.K. and R.H. v. Slovakia (Application No. 15966/04), R.K. v. Czech Republic (Application No. 7883/08) and G.H. v. Hungary (Application No. 54041/14). The case of Hudorovič and the other applicant v. Slovenia (Applications Nos. 24816/14 and 25140/14) concerns members of Roma minority living in a settlement in which they have no access to basic infrastructure such as water, sanitation and electricity. The lack of clean water results in frequent gastrointestinal diseases, especially among the children. Hence, they among others cannot maintain an appropriate level of hygiene, all of which contributes to frequent health problems. The case in which applicants allege violation of Article 14 of the ECHR in conjunction with Articles 3 and 8 thereof is still pending.

4. Slovene Legislation

4.1. Constitution

Slovenia has either succeeded or ratified the international treaties mentioned above, which regulate procedures for victims of discrimination. Pursuant to Article 8 of the Constitution of the Republic of Slovenia, laws and other regulations must comply with generally accepted principles of international law and with treaties that are binding on Slovenia. Ratified and published international treaties must be applied directly. This means that an individual may refer

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[26] Case of VC. v. Slovakia, European Court of Human Rights, Application 18960/07. Available at: https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-107364%22]} (accessed 25.05.2020).

[27] Case of N.B. v Slovakia, European Court of Human Rights, Application No. 15966/04. Available at: https://hudoc.echr.coe.int/fre#{%22itemid%22:[%22001-111427%22]} (accessed 23.05.2020).

[28] European Union Agency for Fundamental Rights, *Inequalities and multiple*..., op. cit., p. 25.

to those international treaties in the procedures before national institutions, including courts.

The principle of equal treatment is incorporated into the Slovene legal system. According to Article 14 of the Slovene Constitution, in Slovenia "everyone is guaranteed equal human rights and fundamental freedoms irrespective of national origin, race, sex, language, religion, political, or other conviction, material standing, birth, education, social status, disability, or any other personal circumstance". Everybody is equal before the law.

4.2. EU law

As a Member State, Slovenia is obliged to respect the EU law set by the Treaty of the European Union (TEU)[29] and the Treaty on the Functioning of the European Union (TFEU).[30] Prohibition of discrimination has evolved gradually in EU law. The principle of non-discrimination is one of the Union's fundamental values, according to Article 2 TEU. When defining and implementing its policies and actions, the EU is required by Article 10 TFEU to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

Several directives of the EU have been adopted with an aim to eliminate discrimination. Only the Racial Equality Directive (2000/43/EC)[31] gives comprehensive protection from discrimination when it comes to accessing the welfare system and other forms of social security. This includes access to "common" services provided by the state, such as public healthcare, education and the social security system. The actual scope of social protection, which includes social security and healthcare, is unknown because it is not articulated in the Racial Equality Directive and has yet to be interpreted by the European Union's Court of Justice (CJEU). [32]

The Racial Equality Directive prohibits discrimination based on race or ethnicity in the context of employment, but also in accessing the welfare system

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[29] Consolidated version of the Treaty on European Union. *Official Journal of the European Union*, C 326/01. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex-%3A12012M%2FTXT (accessed 12.05.2020).

[30] Consolidated version of the Treaty on the Functioning of the European Union. *Official Journal of the European Union*, C 115/147. Available at: https://eur-lex.europa.eu/resource.html?uri=cellar:41f89a28-1fc6-4c92-b1c8-03327d1b1ecc.0007.02/DOC_1&format=PDF (accessed 12.05.2020).

[31] Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin. *Official Journal of the European Union*, L 180, 19.07.2000, pp. 22–26.

[32] European Union Agency for Fundamental Rights, Council of Europe, *Handbook...*, op. cit., p. 122.

and social security, as well as goods and services. It recognised that, to allow individuals to reach their full potential in the employment market, it is also essential to guarantee them equal access to areas such as health, education and housing.

The Fundamental Rights Charter contains a list of human rights inspired by the rights contained in the constitutions of the Member States, the ECHR and universal human rights treaties such as the UN Convention on the Rights of the Child. Under the title "Equality" (Articles 20 to 26), the EU Charter emphasises the importance of the principle of equal treatment in the EU legal order. Since 2009, as the Treaty of Lisbon entered into force 2009, it became a legally binding document with the same legal value as the EU treaties (Article 6 TEU). As a result, EU institutions, as well as EU Member States, are obligated by the Charter, but only while enforcing EU legislation (Article 51 of the EU Charter). Discrimination on various grounds is prohibited under Article 21 of the EU Charter. Individuals can file complaints if they believe the Charter has been violated by EU legislation or state legislation that implements EU law. Through the preliminary referral procedure established by Article 267 TFEU, national courts can seek guidance from the CJEU on the correct interpretation of EU legislation. These advancements have been supplemented by the establishment of new bodies inside the EU, such as the European Union Agency for Fundamental Rights (FRA) or the European Institute for Gender Equality (EIGE), to promote fundamental rights and equality. Furthermore, the European Network of Equality Bodies (Equinet), which brings together 46 organisations from 34 European states, promotes equality in Europe by supporting and enabling the work of national equality bodies. Member States are required by EU's equal treatment legislation to establish an equality authority to give independent support to victims of discrimination.

The majority of Member States have executed this obligation, either by appointing an existing institution or by establishing a new organisation to carry out the new legislation's tasks. However, there are no precise guidelines for the Member States on how to operate these entities. Until now, European anti-discrimination legislation has only required the establishment of equality committees in the categories of race, ethnic origin and gender. [33]

4.3. Legislation

4.3.1. Protection Against Discrimination Act (PADA)

Slovenia has amended the existing legislation or adopted new regulations to transfer the EU directives into its legal order. PADA defines the purpose and content of the law, which is to provide protection against discrimination for

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[33] Ibidem, p. 112.

individuals based on their personal status.[34] These personal circumstances are "gender, nationality, racial or ethnic origin, language, religion or belief, disability, age, sexual orientation, gender identity or gender expression, social status, property status, education, or any other personal ground" (Article 1). Article 2 PADA provides protection against discrimination in various fields of social life, when enforcing human rights and fundamental freedoms, exercising rights and obligations and in other legal relationships in political, economic, social, cultural, civil or other fields.[35]

PADA has established the Advocate of the Principle of Equality as a self-contained state body in the field of protection against discrimination, a defender or advocate of the principle of equality, and determines its functions and powers. The Advocate is an independent and autonomous state institution providing assistance and support to persons subjected to discrimination when enforcing their rights regarding protection against discrimination in the form of counselling and legal assistance in administrative and judicial proceedings related to discrimination.[36] The competences of the Advocate extend to both public and private sectors.

The Advocate is also mandated to conduct a supervisory inspection. If a supervisory inspection shows a violation of PADA, the Advocate may order elimination of the violations. He may also suggest introducing measures to prevent further discrimination or ban future discrimination (Article 42).

4.3.1.1. Procedure on the request of a victim of discrimination

According to Article 33 PADA, a person who claims to be a victim of discrimination may apply to the Advocate for a review. The latter may also initiate a review of discrimination on its own motion if he or she is aware of the existence of discrimination based on an anonymous proposal, a third-party proposal or otherwise (Article 34). The national authorities, local communities, institutions of public powers and legal and natural persons, upon request, are bound to provide the Advocate with all information, including personal data and documents which the defender urgently needs in order to determine whether, in the case at hand, there is discrimination (Article 37).

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[34] Protection Against Discrimination Act [Zakon o varstvu pred diskriminacijo]. *Official Gazette of the Republic of Slovenia*, Nos. 33/16, 21/18 – ZNOrg.

[35] Advocate of the Principle of Equality, *Annual Report 2017*. Available at: http://www.zagovornik.si/wp-content/uploads/2018/06/Report-of-the-Advocate-of-the-principle-of-equality-for-2017-final.pdf (accessed 20.04.2020).

[36] *Zagovornik načela enakosti, Redno letno poročilo za leto 2018*. Available at: http://www.zagovornik.si/en/ (accessed 30.05.2020).

4.3.1.2. Civil procedure PADA

A person who considers that he or she has been a victim of discrimination may file a lawsuit claiming:

- the cessation of discrimination,
- the payment of compensation for discrimination or
- the publication of a judgment in the media.

Due to exposure to discrimination, a victim of discrimination is entitled to a compensation paid by the person who responsible for discrimination. The compensation shall be recognised in the amount of EUR 500 to 5,000. Such limitation of damages does not exist in the Obligations Code.[37]

In determining the amount of compensation, the duration of discrimination must be considered, the extent of exposure to the discrimination and other circumstances of the case. The request for publication of a judgment in the media is upheld if the court considers, in the light of the circumstances of the case, that the publication of the judgment is necessary to eliminate the consequences of discrimination or to prevent discrimination in other similar cases (Article 39).

To strengthen the position of victims of discrimination in the procedure for the elimination thereof, PADA sets the so-called reversed burden of proof (Article 40). If a victim of discrimination, within the procedure with the Advocate, the competent inspection or other procedure in which he or she alleges to be a victim of discrimination, presents the facts justifying the presumption that the prohibition of discrimination was violated, the alleged violator must prove that, in that case, he or she did not violate the prohibition or that unequal treatment is acceptable in accordance with PADA. This rule does not apply in criminal proceedings.

4.3.2. Health Services Act (HSA)

Legislation in the field of healthcare explicitly prohibits discrimination and regulates procedures to minimise it within the healthcare system. According to Article 45,[38] healthcare professionals and medical associates must carry out medical services in accordance with the accepted medical doctrine, the Code of Medical Deontology and other professional and ethical codes. In carrying out their work, they must address all people under the same conditions equally

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[37] Obligations Code [Obligacijski zakonik]. *Official Gazette of the Republic of Slovenia*, Nos. 97/07, 64/16.

[38] Health Services Act [Zakon o zdravstveni dejavnosti]. *Official Gazette of the Republic of Slovenia*, Nos. 23/05, 15/08 – ZPacP, 23/08, 58/08 – ZZdrS-E, 77/08 – ZDZdr, 40/12 – ZUJF, 14/13, 88/16 – ZdZPZD, 64/17, 1/19 – odl. US, 73/19, 82/20, 152/20 – ZZUOOP, 203/20 – ZIUPOPDVE, 112/21 – ZNUPZ in 196/21 – ZDOsk.ff.

and respect their constitutional and legal rights. The only criterion of priority is the necessity of health intervention.

This provision constitutes the basis of claims for damages if the damage has been caused by the subjects involved in healthcare. It may also include damages caused by discrimination based on ethnic origin. The Obligations Code[39] provides in Article 131 that whoever causes damage to another is obliged to redress it if he or she does not prove that the damage was done without his or her fault.

4.3.3. Patients' Rights Act (PRA)

This law establishes the rights of patients in the Slovene healthcare.[40] In accordance with Article 1 PRA, its purpose is to allow for an equal, appropriate, quality and safe medical treatment based on trust and respect between the patient and the doctor or another healthcare professional. In the exercise of the rights of patients under this Act, everybody is to be respected as a person. A person's moral, cultural, religious, philosophical and other personal beliefs must be respected. Everyone's personality and dignity are to be respected in such a way that no one is socially marked because of their state of health and the causes, consequences and circumstances of the situation or medical treatment which he or she has been given (Article 3).

The patient, among other, is entitled to equal access and treatment in medical treatment and has the right to free assistance in the exercise of his rights (Article 5). According to Article 7 PRA, the patient has the right to be treated equally in medical treatment regardless of sex, ethnicity, racial or ethnic origin, religion or belief, disability, age, sexual orientation or other personal circumstances.

4.3.4. Procedures for the protection of the patient's rights

A patient who considers that the rights laid down in the PRA have been violated may use two procedures according to Article 47. The first remedy at their disposal is the first review of the alleged violation of the patient's rights before the competent person or the provider of healthcare services. It begins with the patient's written or oral application. If not satisfied with the outcome of the first review, the patient may demand review of his or her allegations by the Commission of the Republic of Slovenia for the Protection of the Patient's Rights.

In the procedures set forth by the PRA, a patient may be assisted by the Representative of the Patients' Rights (Article 49). The Representative may advise the patient in an appropriate manner on the content of the rights, modalities

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[39] Obligations Code, op. cit.

[40] Patients' Rights Act [Zakon o pacientovih pravicah]. *Official Gazette of the Republic of Slovenia*, Nos. 15/08, 55/17 and 177/20.

and possibilities of their exercise before or during the treatment. If the patient's right is infringed, the Representative offers concrete guidance for the exercise of rights and proposes possible solutions, helps the patient with lodging of remedies under this law, etc.

4.3.5. The Human Rights Ombudsman

The Human Rights Ombudsman of the Republic of Slovenia is a constitutional category also regulated by the Human Rights Ombudsman Act.[41] It does not fall under the executive, judicial or legislative branch of authority. The Ombudsman is therefore not part of any mechanism of authority, but rather acts as an overseer of authority. The human rights ombudsman an autonomous and independent agency is in relation towards the state bodies.

An individual can turn to the Ombudsman if he or she believes that one or more of his or her rights or fundamental freedoms have been violated by an act or an action of a state body. Among others, the Ombudsman may communicate his opinion to each state or local body, from the perspective of protection of human rights and fundamental freedoms, about the case he is investigating, irrespective of the type or stage of proceedings which are being conducted by the respective body.

4.3.6. Constitutional complaint

Due to a violation of human rights or fundamental freedoms, a constitutional complaint may be lodged against individual acts by which state authorities, local community authorities, or bearers of public authority decided the rights, obligations or legal entitlements of individuals or legal entities (Article 50 of the Constitutional Court Act).[42]

According to Article 51 of the Constitutional Court Act, "a constitutional complaint may be lodged only after all legal remedies have been exhausted. Before all extraordinary legal remedies have been exhausted, the Constitutional Court may exceptionally decide on a constitutional complaint if the alleged violation is manifestly obvious and if irreparable consequences for the complainant would result from the implementation of the individual act". An additional condition for lodging a constitutional complaint is that it must be "lodged within 60 days of the day the individual act against which a constitutional complaint is admissible is served. In especially well-founded cases, the Constitutional Court

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[41] Human Rights Ombudsman Act [Zakon o varuhu človekovih pravic]. *Official Gazette of the Republic of Slovenia*, No. 69/17.

[42] Constitutional Court Act [Zakon o Ustavnem sodišču]. *Official Gazette of the Republic of Slovenia*, Nos. 64/07 – uradno prečiščeno besedilo, 109/12, 23/20 and 92/21.

may exceptionally decide on a constitutional complaint which has been lodged after the expiry of the time limit referred to in the first paragraph of this article" (Article 52).

4.4. Case law in Slovenia – a modest start?

4.4.1. Extra court procedures

Under the PRA, there is no publicly accessible collected data on procedures initiated by individuals. The only possibility is to analyse cases that are decided upon at the Administrative Court of Slovenia in the procedure of administrative dispute.

In the judgement No. I U 1505/2015 of 5 April 2016 the plaintiff, after using both reviews according to the PRA, filed a lawsuit at the Administrative Court of Slovenia claiming that he was a victim of discrimination based on his personal status. The plaintiff claimed that the defendant did not correctly and lawfully reject the plaintiff's request for another review of infringement of the rights of the patient because the doctor did not carry out a review in the field of occupational and sports medicine, but instead directed the plaintiff to the selected physician. The court did not find violations of any constitutional rights.

Some of the cases processed in accordance with PADA did relate to healthcare. In the Report for 2017 of the Advocate of the Principle of Equality, it is noted that out of 17 responses received in 2017, 13 inspection bodies did not deal with any case of discrimination committed by an individual in healthcare. These include the Health Inspectorate and the Public Agency for Medicinal Products and Medical Devices. Even though the Health Inspectorate did not investigate any cases of discrimination in healthcare, although the Advocate received nine applications claiming discrimination in the areas of social protection, also including social security and healthcare. In these cases, the inspectorates discovered that individuals were discriminated against on the basis of their gender, religion or belief, citizenship, sexual orientation, local affiliation and other personal characteristics. In a review of the applications that came into his office, the Advocate found that the most frequently claimed personal ground was disability, followed by gender, religious belief and racial or ethnic origin, all of which appeared in 10 cases.[43]

In the Annual Report for 2018, the Advocate reported that the most commonly claimed personal circumstance of discrimination in cases completed in 2018 was disability (15 cases, or 9.62%). The sum of the personal circumstances of ethnicity, race and ethnic origin was 14 cases, or 8.24% (of which eight cases in the field of race

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[43] Advocate of the Principle of Equality, *Annual Report 2017*, op. cit., p. 27.

and four cases in the field of racial or ethnic origin). The alleged personal circumstance, religion or belief occurred in seven cases, or 4.12%. In 2018 the Advocate concluded seven cases in the field of social protection, including social security and healthcare.[44] The Advocate demanded anonymised data from the inspectorates on cases according to Article 16 PADA and received 18 responses from the inspection bodies in 2018; 13 of those, including the Health Inspectorate, did not report discrimination.[45]

4.4.2. Court procedures

Specialised courts evidently have dealt with the majority of cases involving discrimination. Based on access to the case-law database managed by the Supreme Court of the Republic of Slovenia,[46] it is possible to make a conclusion that most issues in the area of discrimination are decided upon by the labour courts and the Higher Labour and Social Court.[47] The main reason for that is the Employment Relation Act which prohibits discrimination in employment, and these courts decide upon alleged violations of the Act.

In labour-related case No. VIII Ips 230/2015 of 23 February 2016, the Supreme Court explained in detail the arguments which must be stated in the lawsuit by the plaintiff in order to prove he or she was a victim of discrimination. The employer is the one who must prove that he or she did not infringe the principle of equal treatment or a prohibition of discrimination, but only if, in the event of a dispute, the worker mentions the facts justifying the presumption that the prohibition of discrimination has been infringed. It follows from that provision that the burden of proving the existence of discrimination is on the worker. It must contend not only that the worker was not treated equally, but also that the reason for unequal treatment was one of the laws of the circumstances. The arguments must be sufficiently plausible to justify a presumption of infringement of the prohibition of discrimination. When the worker puts forward the relevant claims, the employer is the one who must demonstrate, based on the burden of proof, that the infringement of the prohibition of discrimination has not occurred.

The Higher Labour and Social Court, in judgement No. Pdp 792/2013 of 9 October 2013, found that the defendant (public institution, a hospital) had a serious intention to conclude an employment contract with the plaintiff for

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[44] Zagovornik načela enakosti, *Redno letno poročilo za leto 2018*. Available at: http://www.zagovornik.si/en/ (accessed 27.05.2020), p. 63.

[45] Ibidem, p. 84.

[46] Case-law database, *Iskalnik sodne prakse*. Available at: http://www.sodnapraksa.si/ (accessed 31.05.2020).

[47] Zagovornik načela enakosti, *Redno letno*..., op. cit., pp. 93–95.

the advertised post of a medic-caregiver, companion. It changed its mind about the plaintiff's job after it found out the fact that the plaintiff was HIV-positive. The conduct described by the defendant constitutes an infringement of the prohibition of discrimination as set out in the third paragraph of Article 6 of the Employment Relationships Act. Consequently, the defendant is liable for damages to the plaintiff for the incurred loss of income.

So far, the only judgement of a regular court registered in the case-law database relating to discrimination in healthcare is the judgment of the Maribor Higher Court, No. I Cp 494/2018 of 10 July 2018. The court found that the defendant's treatment of the plaintiff in the dental clinic, as the clinic refused to treat the patient because of his HIV infection, was unlawful. The plaintiff was discriminated against because he could not exercise the right to equal treatment in healthcare. Therefore, the plaintiff suffered a non-pecuniary damage in the form of mental pain, which manifested in feelings of insult, humiliation and disability.

5. A long way to go to eliminate discrimination in healthcare

The presented legislation and case law existing so far shows that in practice the struggle for eliminating discrimination in procedures initiated by individuals has only just begun in Slovenia. The necessary legal basis now exists both in international and internal law, but it will take more time and effort before it is possible to conclude that the system is efficient in practice. Until then, it might seem that the fight against discrimination is futile.

This notion is evident also from the perception of discrimination in Slovenia. At the end of 2017, the Advocate conducted a survey on discrimination in Slovenia, aimed at gaining insight into public opinion about discrimination among the general population and carried out by the Institute for Market Research and Media (Mediana), whose sample frame was the population of the Republic of Slovenia aged 15–75. The survey was carried out on a sample (N = 1011), which was representative for Slovenia by gender, age, region and level of education.[48] About one quarter of the respondents believe that the most frequent targets of discrimination in Slovenia are Roma, followed by homosexuals, refugees and members of the lower social strata. More than a third of respondents (36%) believe that in the recent years the situation of inequality and discrimination in the country has deteriorated. The respondents' answers to the question of how to combat inequality and prevent discrimination paint a more worrying picture, as more than a third (36%) of them think that the fight against inequality is not appropriately (or not at all) prevented or eliminated. The respondents were

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[48] Advocate of the Principle of Equality, *Annual Report 2017*, op. cit., p. 39.

of the opinion that discrimination is the most widespread in the area of labour and employment, justice, police procedures, followed by social and health care.[49]

The presented data show that Slovenia is not immune to various forms of discrimination, including discrimination based on ethnic origin in healthcare. In order to make the existing legal remedies more efficient through creating case law, it would be necessary to inform the potential victims of discrimination on the remedies and forms of free legal aid they have at their disposal.

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[49] Ibidem.

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The recognised barriers in accessing healthcare services in obstetrics and gynaecology clinical setting: The case of immigrant women

1. Introduction

The social and political values which underlie every society also constitute the foundations of the welfare state and the existing healthcare system. Therefore, the health services rendered exacerbate health inequalities if their provision and accessibility are compromised. Hence, in terms of tackling health inequalities, it is vital to identify groups which are potentially vulnerable to various health risks and which may not have sufficient access to health services within the system.[1] One of the groups who find access to healthcare most difficult are migrants. When accessing the healthcare system, they often face a number of structural and political barriers, which may, in turn, lead to their needs being unmet and the quality of the healthcare received poor.[2] In addition, personal factors like age, gender, socio-economic status, ethnicity, language ability, proximity to healthcare services, social exclusion, health-seeking behaviour and health-related beliefs make access to the health system even more difficult. Along with barriers at the health system level, e.g., the public health policy and the legal status of migrants within the host country's health system, the specificities of individual health systems also have an impact on their access to healthcare.[3]

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[1] Diana Gil-Gonzalez, Mercedes Carrasco-Portino, Carmen Vives-Cases, Andrés A. Agudelo-Suarez, Ramón Castejon Bolea, Elena Ronda-Perez, "Is health a right for all? An umbrella review of the barriers to health care access faced by migrants". *Ethnicity and Health* 20 (2015), pp. 523–541.

[2] Lucinda Hiam, Nikos Gionakis, Seth M. Holmes, Martin McKee, "Overcoming the barriers migrants face in accessing health care". *Public Health* 172 (2019), pp. 89–92.

[3] Sally Hargreaves, Jon S. Friedland, "Impact on and use of health services by new migrants in Europe". In: Felicity Thomas, Jasmine Gideon (eds.), *Migration, Health and Inequality*. London, New York 2013, pp. 27–43.

Lack of knowledge due to ignorance, ethnocentricity, stereotyping or racial prejudice in the receiving societies has the potential to deprive people of their human rights and preclude them from receiving appropriate help and support.[4] Migrants are subject to more diffuse forms of social exclusion which is manifested at the level of individual as well as collective experience, which may further impact their already poor health status, lower quality of life and curtailed access to social and health services.[5]

As stated by the International Organisation for Migration,[6] the fact that migrants represent a non-homogeneous population group with equally non-homogeneous needs or health-related vulnerabilities makes it essential for the fields of migration and healthcare to fully understand the concepts and factors of health vulnerability and health resilience. The former may be defined as the extent of an individual's inability to predict, manage, prevent and recuperate from a disease and its effects. Health vulnerability is associated not only with low socioeconomic status, but may occur when a population group lives in isolation and insecurity, exposed to risk, shock or stress, as is the case during and after migration. Health resilience, on the other hand, stems from the accessibility of the resources which an individual needs in order to tackle or resist a health risk. While these resources may be physical or material in nature, they may also include the skills or qualities possessed by individuals and their social networks. In this context, a key dimension which requires particular consideration is gender.[7] There is significant empirical evidence that migration affects the health of female migrants to a greater extent than it does the health of male migrants.[8] In practice, any exclusion from the health system for migrant women means a delayed access to screening, treatment and care, as well as limited access to birth control and pregnancy termination, and heightened levels of discrimination and gender-based violence.[9]

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[4] Mary Tilki, "Human rights and health inequalities: UK and EU policies and initiatives relating to the promotion of culturally competent care". In: Irena Papadopoulos (ed.), *Transcultural Health and Social Care: Development of Culturally Competent Practitioners*. Edinburgh 2006, pp. 25–44.

[5] Gil-Gonzalez et al., *Is health*..., op. cit.

[6] International Organisation for Migration, *World Migration Report 2020*. Available at: https://publications.iom.int/system/files/pdf/wmr_2020.pdf (accessed 28.11.2019).

[7] Ibidem.

[8] Richard M. Adanu, Timothy R. Johnson, "Migration and women's health". *International Journal of Gynecology and Obstetrics* 106 (2009), pp. 179–181; Hiranthi Jayaweera, "Access to healthcare for vulnerable migrant women in England: A human security approach". *Current Sociology* 66 (2018), pp. 273–285.

[9] Alyna C. Smith, Michele LeVoy, Tahir Mahmood, Charlotte Mercer, *Migrant Women's Health Issues: Adressing Barriers to Access to Health Care for Migrant Women with Irregular Status*. Available at: http://www.euro.who.int/__data/assets/pdf_file/0017/330092/6-

Norredam and Krasnik[10] identified and divided the barriers in migrants' access to the healthcare system into two categories, associating the first category, i.e. "formal barriers to access", with health policies and organisation of healthcare systems, and the second category, i.e. "informal barriers to access", with language, communication, sociocultural factors and "newness", or a complex interaction between these factors. Two years later, Hargreaves and Friedland[11] also categorised the key barriers to accessing healthcare services by dividing them into two groups: system and provider-level barriers and patient-level barriers. Gil-Gonzalez et al.[12] maintain that structural barriers significantly affect migrants' access to the health system. This study identified extremely significant structural barriers in countries with a non-universal health system and high cost of medication. In countries with a mixed or universal health system, the structural barriers were found to be related to organisational factors of delivering care (legal restrictions for certain groups, payment rules, lack of referral and cohesion between service tiers). In addition, the barriers generated by healthcare providers (individual level) were related to linguistic problems and cultural differences which contributed to mutual misunderstandings. The lack of relevant health information was also perceived as a significant barrier.[13]

The barriers to accessing the health system might vary depending on the type of services from country to country, but also among different migrant groups. It is therefore essential to study the structural and personal barriers which are related to organisational behaviours. Healthcare providers must acknowledge the existence of barriers to accessing healthcare as well as health inequalities which contribute to accessing healthcare.[14] Hence, the aim of the study, which was a part of a large-scale EU-funded project Interreg Italia-Slovenia V-A 2014-2020 INTEGRA, was to explore healthcare professionals' experiences and recognised barriers when delivering care to immigrant women in institutional settings.

Migrant-womens-health-issues-irregular-status.pdf?ua=1 (accessed 12.12.2019); Nicole C. Schmidt, Vanessa Fargnoli, Manuella Epiney, Olivier Irion, "Barriers to reproductive health care for migrant women in Geneva: A qualitative study". *Reproductive Health* 15 (2018), p. 43. Available at: https://doi.org/10.1186/s12978-018-0478-7.

[10] Marie Nørredam, Allan Krasnik, "Migrants' access to health services". In: Bernd Rechel, Philipa Mladovsky, Walter Devillé, Barbara Rijks, Roumyana Petrova-Benedict, Martin McKee (eds.), *Migration and Health in the European Union*. Maidenhead 2011, pp. 67–78.

[11] Hargreaves, Friedland, *Impact on*..., op. cit., pp. 27–43.

[12] Gil-Gonzalez et al., *Is Health*... op. cit., pp. 523–541.

[13] Ibidem.

[14] Schmidt et. al., "Barriers...", op. cit.

2. Methods

The research design for this study was based on a qualitative approach. The focus group method was employed, which enabled interactions between the participants and thus generated data that would not emerge if other methods of data collection, such as individual interviews, were used.[15] This approach is particularly useful for the exploration of new topics and examination of complex issues involving values and beliefs which underlie behaviour.[16] The focus group consisted of eight participants, i.e., healthcare professionals employed in clinical settings at the secondary level of healthcare (hospital, e.g. maternity clinic). The focus group, which was held in the form of a one-time meeting, was organised in August 2018.

The data were collected using a semi-structured interview as a method designed to ascertain subjective responses from participants regarding a particular situation or phenomenon they have experienced. It employs a relatively detailed interview guide and may be used when there is sufficient objective knowledge about an experience or phenomenon, but the subjective knowledge is lacking.[17] The interviews were audio-recorded and transcribed verbatim. The interview guide included 11 main questions (for example "Can you tell me about your perspective on migrants in clinical settings?", "Can you tell me about your most common barriers when delivering care to migrant women?", "Can you tell me about your experiences with interpreters/translators?", "Can you tell me about your positive experiences with migrant patients?", "Can you tell me about your negative experiences with migrant patients?", "Can you tell me whether you have ever been asked to abandon any routine procedures or practices due to culture issues?", "Can you tell me what healthcare professionals as yourself need to deliver culturally congruent care?"). In some cases, additional sub-questions were applied so that clarifications of certain aspects of discussion could be clarified.

The qualitative data analysis was performed using the NVivo ver. 12 (QRS International, Victoria, Australia) computer software. The transcripts were analysed using thematic analysis, which is a method used for identifying, analysing, organising, describing and reporting themes found within a dataset.[18] The thematic

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[15] Rosalind Bluff, "Interviewing in qualitative research". In: Elizabeth R. Cluet, Rosalind Bluff (eds.), *Principles and Practice of Research in Midwifery*. Edinburgh 2006, pp. 221–242.

[16] Martha Ann Carey, "Focus groups". In: James D. Wright (ed.), *International Encyclopedia of the Social & Behavioral Sciences*. Oxford 2015, pp. 274–279.

[17] Michele J. McIntosh, Janice M. Morse, "Situating and constructing diversity in semi-structured interviews". *Global Qualitative Nursing Research* 2 (2015). Available at: https://doi.org/10.1177/2333393615597674.

[18] William J. Gibson, Andrew Brown, *Working with Qualitative Data*. London 2009.

analysis was performed in six phases: (1) familiarisation with the data, (2) generation of initial codes, (3) search for themes, (4) review of themes, (5) definition and naming of themes, (6) preparation of the report.[19]

All the participants were informed about the aims, objectives and research method used, whereby anonymity and voluntary participation were emphasised. The participants who decided to take part in the qualitative study were asked to give a written consent. The study was conducted in accordance with the Helsinki-Tokyo Declaration, the Code of Ethics for Nurses and Nurse Assistants of Slovenia and the set of recommendations on ethics in qualitative research. The study was part of the INTEGRA project and co-funded by the cross-border co-operation Programme Italy-Slovenia 2014–2020 financed by the European Regional Development Fund. The study was approved by the National Medical Ethics Committee (26.10.2017; 0120-544/2017/7).

3. Results

All eight participants were female and were employed at the Gynaecological and Maternity Hospital Postojna. Among them, five had obtained a bachelor's degree in nursing and three were nursing assistants (vocational school). The average tenure of the participants was 18.25 years (SD = 12.80), where the shortest tenure was three years and the longest 35 years. At the time of the interview, all the participants were directly involved in delivering nursing care to women patients.

The preliminary analysis conducted prior to undertaking the thematic analysis included identifying word frequencies to get an overview of the content, and cluster analysis, e.g. comparison of word similarity and coding similarity with regard to individual cases (participants). The items clustered by word similarity revealed a strong relationship between the cases and confirmed the clustering in the initial thematic analysis. The items clustered by coding similarity also demonstrated strong relationships between the codes, which were measured by the Jaccard Index (J = 1). The thematic analysis of healthcare professionals' experiences and perceptions regarding the barriers in delivering care to migrant women in clinical settings identified three main themes: (1) language barrier, (2) culturally defined women's roles, and (3) (perceived) insufficient cultural knowledge.

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[19] Lorelli S. Nowell, Jill M. Norris, Deborah E. White, Nancy J. Moules, "Thematic analysis: Striving to meet the trustworthiness criteria". *International Journal of Qualitative Methods* 16 (2017). Available at: https://doi.org/10.1177/1609406917733847; Gibson, Brown, *Working*..., op. cit.

3.1. Language barrier

The language barrier was recognised by the participants as one of the main obstacles in delivering healthcare in institutional settings.

> "The problem is the language, which we do not know how to speak."
>
> "Not knowing how to communicate properly is a problem. It is hard for these people and it is hard for us [...]."

The participants also mentioned the practices they used in order to overcome this barrier, since, as reported by them, this question of language lacks an appropriate systemic solution. As they all emphasised, "they are left to their own devices" to find, in some cases, very innovative solutions. The Albanian language is perceived as the most challenging for healthcare professionals (for example, many patients understand or speak English; there are several language commonalities the Slovenian language shares with other languages within the Slavic language group, etc.). To tackle this problem, translation/interpreting was either provided by the husband, which some healthcare professionals deem as less than desirable; by women from an Albanian community living nearby; there had also been cases where the migrant women brought someone along for translation/interpreting; cases where a person of Albanian origin working in the hospital helped in translation/interpreting; and cases where a language dictionary was used, either in the form of a printed book or the "Google Translate service" on their mobiles, which was perceived as less desirable by the participants.

> "The biggest problem are Albanian patients because they don't understand Croatian or Serbian. We can find someone in the hospital who speaks Italian, English or any other world language. That's not a problem. They are the biggest problem, that is why we often use a woman who lives near the hospital and is of Albanian origin. In certain cases, migrant women themselves bring along a woman who translates for them."
>
> "Albanian is a very specific language. We do not have such major problems with other languages. In the past, we were fortunate to have an employee in the hospital who spoke Albanian, however now we do not have any other formal translator in the hospital to help us with the translation [...]."
>
> "After birth we sometimes have problems with patients speaking Albanian. We have the husband on the mobile and he is translating directly. This is problematic from various perspectives, but even more so when it comes to a practical demonstration of how to nurse a new-born."

> "My colleagues [meaning midwives] told me that they sometimes used Google Translate services, which is not good. They type the text in the mobile and give it to the patient to read. This is not good; however, it is one of the ways in which improvisation resolves the issue of the language barrier."

The problem the healthcare professionals see is the lack of a 24/7 translation service. Obstetrics is a discipline which requires assistance at any time, either day or night. What they see as especially problematic is the fact that during the night there are fewer possibilities for ensuring translation to patients. The possibility not to explain things to patients seems very frustrating for all the participants. One of them described one of her experiences:

> "I was present at the admittance of a patient from Syria and we could not communicate appropriately due to the language barrier. She was completely frightened. You feel sorry for her, it is just you simply do not have anyone to use to translate for her. She was arrested at the border and brought to the hospital because she was pregnant [...]."

3.2. Culturally defined women's roles

The second theme addresses an issue that needs specific attention in the future within the health and social welfare systems. It seems that culturally defined women's roles still greatly affect women's autonomy in relation to their body and choices they make. According to the majority of the participants, the husband or immediate family members interfere in women's autonomy in clinical settings. This was seen as very challenging by all healthcare professionals. Until recently, they had been used to communicate only and directly with the patient about the patient's medical condition and care that she needed; however, some of the participants reported on cases of Muslim women whose husbands wanted to be present at vaginal examinations or demanded information about their wife's medical status and/or decided on her behalf. Healthcare professionals perceived such cases as "extreme" and emphasised that they were often faced with an ethical dilemma since they realised that professional codes of conduct suggested the opposite. In this context, healthcare professionals are well aware of the fact that if they do not allow, for example, the presence of a husband during vaginal examination, there might be no "next time" for the woman to visit the gynaecologist or to attend the screening (e.g. PAP test).

> "The aim is that we treat every woman. Thank goodness he has brought her in to see the doctor. If we didn't treat her according to his convictions, we wouldn't see her again in the health system."

> "We always make some sort of compromises. Even such that we allow the husband to be present at the vaginal examination. If you asked me, I would not allow this. Moreover, women do not oppose that. From a certain perspective this is OK, because I know that we would not see her again at the doctor's office otherwise."

> "The male doctors are always worried if a woman is admitted to hospital for giving birth and does not allow a male doctor to be present during labour and birth."

The participants also listed a few cases from the clinical setting where a female patient (Muslim), accompanied by her husband, did not understand a word of Slovenian when talking to healthcare professionals (midwife or nurse); however, when her husband left the hospital (or just left the room) the woman understood Slovenian and tried to respond in Slovenian.

> "They don't understand anything. You cannot talk to them. We call for a translator if possible; however, when the husband leaves the room or hospital, they suddenly start speaking Slovenian."

> "I will never forget this. She was in the delivery room all night and we agreed on everything. I respected her wishes and she was really talking non-stop, however when her husband was present, she did not say a word. Even he didn't know she understood Slovenian."

> "She doesn't dare to speak Slovenian in front of a man (her husband)."

3.3. (Recognised) insufficient cultural knowledge

In several cases, healthcare professionals showed, directly or indirectly, a lack of cultural knowledge about patients from other cultures they encountered. For example, health-related behaviour which differs from what is socially accepted is often seen as an attempt at an "exploitation of the health system" by migrant women or their families. Healthcare providers perceive this as unjust in comparison to other patients. In this context, a few participants gave some examples of such perceived "exploitation" related to the failure to comply with hospital rules (e.g., a high number of visitors despite limitations to only one visitor; visit to the doctor, regardless of the day and time, without a previous appointment; behaviour perceived as inappropriate). Stereotypes and, in two cases, prejudices came to light, as well as apparent intolerance in one case.

> "The problem are the visits in the hospital. Slovenian patients are only allowed visits by their partner, while foreign patients have all their family members visiting them – half a busload, and you have trouble convincing them that hospital visits are limited to one person. They are not prepared to conform to our cultural habits."

> "[...] they tell one another how things in the health system work, and then they exploit the system [...] and then you see that this is not a coincidence. One of us [meaning Slovenians] would never dare to do such things."

> "[...] We will lose our nerves if they don't respect our (pause). Now we slowly understand that they exploit the system. If everybody else has an appointment [...]. They come in on Thursday instead of Wednesday."

Despite everything, the participants pointed out that they tried to avoid a conflict (cultural conflict) and confessed that this could be quite challenging.

> "These are really some different cultural habits and sometimes it is quite challenging to see things from their perspective."

The perception of "exploitation", as well as general impressions influenced by the public image seem to stem from a lack of knowledge about cultures other than their own, as well as from the existing stereotypes and prejudices about certain cultures or migrants in general. At the end of the discussion, they openly confessed that they were lacking knowledge about the cultural habits of their patients.

> "We need to talk among ourselves about this. We need to learn about cultures we encounter and also to learn from their experience. This will enrich us and prepare us for future challenges."

> "It has come to that now. You could say in the past that they did not understand our habits. Now we talk more, you observe things. They (meaning migrant women) have their qualities that we do not have."

4. Discussion

For many, migration is seen as a complex and multi-staged process rather than a singular transition from one place to another. Population migration, which we have been witnessing over the last decade, has undoubtedly become a key global policy issue. Important questions are now being raised regarding the rights, entitlements and equalities available to migrants who are seeking to access key welfare services in host countries and communities.[20] In this context and from the health system's perspective, migrants clearly provide organisational challenges to health systems across Europe and worldwide, as many of these

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[20] Felicity Thomas, Jasmine Gideon, "Introduction". In: Felicity Thomas, Jasmine Gideon (eds.), *Migration, Health and Inequality*. London, New York 2013, pp. 1–9.

systems are not prepared to receive and provide appropriate healthcare services to so many culturally diverse patients.[21] Due to barriers related to legislation, economics and administration, such challenges are reflected not only in the lack of accessibility of healthcare services, but also in the lack of available services in translation and cultural mediation, lack of familiarity with the entitlements and services available, as well as in the organisation and coordination between these services, and finally also in the difficulty obtaining reliable information on migrants' health status and medical history.[22]

Individuals or groups seek healthcare with unique cultural needs, beliefs, and behaviours.[23] Migrant populations have specific health needs. Their patterns of disease may differ greatly from those seen in the local population; moreover, they are often placed at the margins of society. Migration seems to affect women's health much more than men's.[24] Evidence suggests that, in comparison to local women, migrant women face higher risks of perinatal morbidity and mortality, problems related to pre- or neonatal period (preterm birth, low birth weight, congenital anomalies, etc.) and other associated problems.[25] Therefore, there is an urgent need for a deeper understanding of the complexity of the situation in which migrant women are placed in order to improve access to the health system and meet their needs in vulnerable situations.[26]

Very often, migrants have reduced access to healthcare services due to communication problems, lack of knowledge of the services available, and the influence

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[21] Mirko Prosen, Sabina Ličen, Urška Bogataj, Doroteja Rebec, Igor Karnjuš, "Migrant women's perspectives on reproductive health issues and their healthcare encounters". In: Sabina Ličen, Igor Karnjuš, Mirko Prosen (eds.), *Women, Migrations and Health: Ensuring Transcultural Healthcare*. Koper 2019, pp. 117–137.

[22] Antonio Chiarenza, Marie Dauvrin, Valentina Chiesa, Sonia Baatout, Hans Verrept, "Supporting access to healthcare for refugees and migrants in European countries under particular migratory pressure". *BMC Health Services Research* 19 (2019). Available at: https://doi.org/10.1186/s12913-019-4353-1.

[23] Patricia L. Hart, Nicole Mareno, "Nurses' perceptions of their cultural competence in caring for diverse patient populations". *Online Journal of Cultural Competence in Nursing and Healthcare* 6 (2016), pp. 121–137.

[24] Jayaweera, "Access...", op. cit., pp. 273–285.

[25] Eva K. Robertson, "'To be taken seriously': Women's reflections on how migration and resettlement experiences influence their healthcare needs during childbearing in Sweden". *Sexual* and *Reproductive Healthcare* 6 (2015), pp. 59–65; Anna Reeske, Oliver Razum, "Maternal and child health – From conception to first birthday". In: Rechel et al. (eds.), *Migration*..., op. cit., pp. 139–153; Nicola Heslehurst, Heather Brown, Augustina Pemu, Hayley Coleman, Judith Rankin, "Perinatal health outcomes and care among asylum seekers and refugees: A systematic review of systematic reviews". *BMC Medicine* 16 (2018). Available at: https://doi.org/10.1186/s12916-018-1064-0.

[26] Robertson, "'To be taken...," op. cit.

of many other factors related to their experiences before migration, during migration and after their arrival in the host country, which may affect their health. Health services are an important social determinant of health, and studies have shown that migrants' access to health services affects their healthcare.[27] Structural barriers to healthcare, especially those involving their legal status and the already mentioned organisation of the healthcare system, often have a weightier impact than social or cultural barriers.[28] Heslehurst et al.[29] found that migrant women's experiences of care included negative communication, discrimination, poor relationships with health professionals, cultural clashes and negative experiences with clinical interventions.

Policy makers and other regulatory bodies have the ability to improve migrants' access to the health system and to overcome structural barriers, one of which (i.e. the language barrier) was also pointed out in this study. Overcoming structural barriers depends on a clear statement of entitlements under law, their communication to migrants and healthcare professionals, appropriate implementation measures, not linking healthcare to a person's migration status, and provision of protection and assistance to victims of trafficking.[30] Currently, the Slovenian health system lacks effective systemic solutions for tackling the language barrier in healthcare institutions. Lipovec Čebron et al.[31] found that, in the aspect of language, the Slovene health system is governed by a pronounced monolingual attitude, which is reflected in the lack of appropriate interpretative services and possible measures that would contribute to a more effective communication between foreign patients and healthcare professionals. Moreover, numerous studies from around the world have clearly demonstrated that language barriers can affect the delivery of health services and may influence patient outcomes.[32] Apart from the language barrier, lack of interpreters or cultural mediators also affects migrants' access to healthcare and, in turn, gives

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[27] Gil-Gonzalez et al., *Is health*..., op. cit.; Nørredam, Krasnik, "Migrants'...," op. cit., pp. 67–78.

[28] Yonina Fleischman, Sarah S. Willen, Nadav Davidovitch, Zohar Mor, "Migration as a social determinant of health for irregular migrants: Israel as case study". *Social Science and Medicine* 147 (2015), pp. 89–97.

[29] Heslehurst et al., "Perinatal...", op. cit.

[30] Paola Pace, "The right to health of migrants in Europe". In: Rechel et al. (eds.), *Migration*..., op. cit., pp. 56–66.

[31] Uršula Lipovec Čebron, Lea Bombač, Nike Kocijančič Pokorn, Miha Lučovnik, "Monolingual health? Linguistic barriers in Slovene healthcare experienced by migrant/refugee women". In: Ličen, Karnjuš, Prosen (eds.), *Women*..., op. cit., pp. 139–153.

[32] Allison Squires, Sarah Miner, Eva Liang, Maichou Lor, Chenjuan Ma, Amy Witkoski Stimpfel, "How language barriers influence provider workload for home health care professionals: A secondary analysis of interview data". *International Journal of Nursing Studies* 99 (2019). Available at: https://doi.org/10.1016/j.ijnurstu.2019.103394.

rise to health disparities. Kohlenberger at al.[33] pointed out that the lack of interpreters significantly contributes to an early use of health services, severe psychological symptoms and lower use of preventive health services such as screening and immunisation programmes. All this contributes to higher follow-up costs for the secondary and tertiary levels of healthcare. Interpreters or cultural mediators would enable a more effective communication and care for migrants who do not speak the language spoken in the host country and could contribute to improving the treatment outcomes and increase the level of satisfaction with overall health services.[34] However, it needs to be emphasised that the role of an interpreter or cultural mediator is not simply to translate. An interpreter needs to be a formally trained professional, since, as revealed by the findings of this study, informal interpreters, especially if they are family members (e.g., the husband), do not necessarily act in the best interest of the woman in the process of interpreting. As stated by Schouten,[35] the informal interpreter may find it difficult to balance the expectations of healthcare providers on one hand and patients on the other, and thus feel overwhelmed by their task.

Policy makers are not the only ones who should address the language barrier. At the operational level of the health system, healthcare institutions should also more carefully address the issue of the language barrier. This can be done by re-examining the current practices, translating certain health promotion/health education materials into different languages in relation to the demographic structure of the patients, placing emphasis on a more pronounced use of pictograms within the premises of the institution, introducing social/cultural anamneses as part of traditional biomedically oriented anamneses, and organising prenatal education in the form of individual or group counselling. When facing homogeneous populations of pregnant migrant women, emphasis should also be placed on the continuity of care after patients' discharge from hospitals and more intense involvement of the community nurse. The role of the latter is often overlooked in bridging the gap when discussing social integration and preventing health disparities.[36]

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[33] Judith Kohlenberger, Isabella Buber-Ennser, Bernhard Rengs, Sebastian Leitner, Michael Landesmann, "Barriers to health care access and service utilization of refugees in Austria: Evidence from a cross-sectional survey". *Health Policy* 123 (2019), pp. 833–839.

[34] Titaree Phanwichatkul, Elaine Burns, Pranee Liamputtong, Virginia Schmied, "The experiences of Burmese healthcare interpreters (Iam) in maternity services in Thailand". *Women and Birth* 31 (2018), pp. e152–e161.

[35] Barbara Schouten, "Toward a theoretical framework of informal interpreting in health care: Explaining the effects of role conflict on control, power and trust in interpreter-mediated encounters". In: Elisabeth A. Jacobs, Lisa C. Diamond (eds.), *Providing Health Care in the Context of Language Barriers: International Perspectives*. Bristol 2017, pp. 71–92.

[36] Mirko Prosen et al., *Report About the Migrant Women's Population Characteristics, Their Sexual and Reproductive Health and Social Integration: The Case of Slovenia – Rapporto*

The findings also point out that women's autonomy in clinical settings is being challenged by her own cultural traditions. In some cultures, specific gender roles and patriarchy influence women's choices regarding reproductive health and thus create numerous ethical dilemmas to healthcare professionals, which they have not encountered before. As revealed by a study conducted by Urpis,[37] the patriarchal system, which most often compels women to be dependent on their husbands, is very much internalised by women, so that even when women are given the opportunity for independency, they refuse it. These issues need to be further addressed by taking measures that would empower migrant women and prevent them from further social exclusion. From the perspective of healthcare professionals, the already mentioned community nurse is in an ideal position to improve people's health literacy (for example, informing women about the existing screening programmes) and assist in social inclusion. Social support by healthcare professionals has been established as a key factor in accessing maternity care, even though this in itself is not sufficient to overcome problems of social isolation.[38]

There was a noticeable level of cultural awareness among the healthcare professionals in the focus group; however, there were cases where prejudices did nevertheless come to light. This is not surprising as the prejudices reflected the media created images of migrants. What seems positive is that healthcare professionals did recognise their lack of cultural knowledge. As elaborated by Mengesha et al.[39], cultural awareness is crucial if we wish to increase sensitivity and understanding, avoid assumptions and generalisations, and deliver culturally congruent care. Cultural awareness in itself facilitates the development of cross-cultural competences which are essential in delivering holistic and culturally appropriate care. Cross-cultural competence can be defined as the ability of a healthcare professional to provide the patient, family or community with culturally

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sulle caratteristiche della popolazione femminile migrante, la loro salute sessuale e riproduttiva e l' integrazione sociale: Il caso della Slovenia – Poročilo o značilnosti ženske migrantske populacije, njihovega spolnega in reproduktivnega zdravja in družbene integracije: primer Slovenije. Izola, Postojna 2018.

[37] Ornella Urpis, "Sexual and reproductive health as an indicator of social integration: The obstacle of a patriarchal culture and forced marriage in migrant communities". In: Ličen, Karnjuš, Prosen (eds.), *Women...*, op. cit., pp. 23–34.

[38] Gina M.A. Higginbottom, Myfanwy Morgan, Mirande Alexandre, Yvonne Chiu, Joan Forgeron, Deb Kocay, Rubina Barolia, "Immigrant women's experiences of maternity-care services in Canada: A systematic review using a narrative synthesis". *Systematic Reviews* 4 (2015). Available at: https://doi.org/10.1186/2046-4053-4-13.

[39] Zelalem B. Mengesha, Janette Perz, Tinashe Dune, Jane Ussher, "Challenges in the provision of sexual and reproductive health care to refugee and migrant women: A methodological study of health professional perspectives". *Journal of Immigrant and Minority Health* 20 (2018), pp. 307–316.

sensitive and competent care, taking into consideration their values, convictions, customs and habits and incorporate them into treatment planning. Healthcare professionals should accept and respect cultural diversity, the awareness of which is acquired through knowledge and development of professional skills.[40] Gil-Gonzáles et al.[41] stress the fact that barriers arise when healthcare providers are not provided with the necessary tools through which they could enhance their cultural competence. Moreover, barriers may also occur when the social and cultural differences between the professional and the patient are not recognised, examined and accepted.

In the past, the curricula of institutions educating for healthcare professions have not devoted enough attention to the social and cultural basis of healthcare, which has resulted in a health system conceived on the concept of a "common" body of patients with no recognition of individuality.[42] Even though fast, unpredictable and dynamic migration trends have triggered changes within the health system, the main challenges for healthcare professionals still include lack of awareness of the migrants' specific healthcare problems, language and intercultural communication problems, as well as access and integration of migrants into the healthcare system.[43] Therefore, educational institutions educating healthcare professionals at all levels should incorporate transcultural contents into formal curricula and strive for life-long learning of healthcare professionals to include cross-cultural education as a permanent form of informal education. As a priority, the supportive staff working in healthcare institutions (administrative staff etc.) should also receive such training.[44]

The study has some limitations which need to be taken into account. The first is related to the sample size – according to Hennink, Kaiser and Weber[45], two or more focus groups provide additional understanding of the issue. In line with the project, we explored the current situation in only one regional maternity hospital; however, expanding the sample is something that needs to be considered for future research. Furthermore, medical doctors should be included in the sample to a greater degree. Even though the moderators of the focus group

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[40] Mirko Prosen, "Developing cross-cultural competences: Opportunity for ensuring health and healthcare equality and equity". *Slovenian Nursing Review* 52 (2018), pp. 76–80.

[41] Gil-Gonzalez et al., "Is health...", op. cit., pp. 523–541.

[42] Marie McKeary, Bruce Newbold, "Barriers to care: The challenges for Canadian refugees and their health care providers. *Journal of Refugee Studies* 23 (2010), pp. 523–545.

[43] Marie-Louise Luiking, "Migrants' experiences in the healthcare system". In: Ličen, Karnjuš, Prosen (eds.), *Women*..., op. cit., pp. 95–105.

[44] Mirko Prosen, *Report*..., op. cit.

[45] Monique M. Hennink, Bonnie N. Kaiser, Mary Beth Weber, "What influences saturation? Estimating sample sizes in focus group research". *Qualitative Health Research* 29 (2019), pp. 1483–1496.

tried to prevent the data from being negatively influenced by group dynamics,[46] they could not avoid this to its fullest in the section focusing on prejudices towards migrants. In this part of the transcript, member checks and peer debriefing with colleagues were also performed.

5. Conclusion

The increasing migration flows to Europe and migrants waiting at its borders represent additional challenges for the public health system and healthcare providers. In the majority of cases, the services within the current health systems have not been designed for such a high number of culturally diverse groups of patients and have not taken into account the different barriers in accessing health system for migrants. If we accept the fact that health is a basic human right and that each person is entitled to it, then we need to also acknowledge the fact that policy makers must produce conditions enabling access to healthcare. Understandably, this is no easy task for governments; however, there still exist issues and barriers which cause health inequalities which no longer have a place in the 21st century.

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[46] Carey, *Focus*..., op. cit., pp. 274–279.

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William Wang, Jacek Kornak

A place of safety in crisis: The spatial examination of mental health crisis care facility in the UK

1. Introduction

The increased awareness of mental healthcare in recent decades has highlighted the level of historic prejudicial investment and treatment of mental health patient group in the UK.[1] This research draws on the disparity by providing a novel way of looking at the patient's spatial experience as a phenomenological reality in the Emergency Department (ED) – the threshold between public and inpatient care and where the inequality in treatment and access for patients with mental health disorders is pronounced.

The quality of clinical practice for individuals at the margins of our society is an indicator of our social values. These include effectiveness of a clinical pathway, the efficiency of care delivery and the access and availability of clinical facilities. As such, the architecture of the treatment facility is a physical manifestation of our values, as it embodies the availability of funding, resources and aspiration.

Studies have shown patients in mental health crisis to have poorer perceived experience of the ED compared to other patient groups.[2] Attendance continues to grow[3] at a rate far higher than the growth rate of the population in the UK, and patients often struggle to receive timely and consistent quality of treatments[4] – as confirmed by patients interviewed in this research process, which ranged from four hours to 98 hours. With the potential length of stay,

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[1] Mental Health Taskforce, *Implementing the Five Year Forward View for Mental Health*. Available at: https://www.england.nhs.uk/wp-content/uploads/2016/07/fyfv-mh.pdf (accessed 05.10.19); Care Quality Commission, "Right here, right now". In: idem, *Right Here, Right Now: Mental Health Crisis Care Report*. London 2015, pp. 1–12.

[2] Ibidem.

[3] NHS Digital, *Hospital Accident and Emergency Activity*. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/hospital-accident--emergency-activity/2018-19 (accessed 12.11.2019).

[4] "Healthy London Partnership". In: *Mental Health Crisis Care for Londoners: London's Section 136 Pathway and Health Based Place of Safety Specification*. London 2017, pp. 6–23.

the environmental design of the ED is therefore one of the major factors that can contribute to the wellness and psychological condition of a patient.

The built environment is a vital part of healthcare delivery and patient care.[5] Patients arrive in the ED in their most vulnerable states, but it was not until 2015 that government policy started to recommend dedicated facilities for patients in mental health crisis in urgent and emergency care, known as the Health-Based Places of Safety (HBPOS).[6] These spaces intended to provide a safe environment for individuals detained under The Mental Health Act 1983, section 136 (MHA), to be clinically assessed. This project looks at one such facility implemented in Charing Cross Hospital, London, and discusses its relevance to improve patient access and quality of care.

This paper focuses on the environmental aspect of the research and is presented in three main sections. The Model of the Past points to the old facility in Charing Cross Hospital, the Present Model presented the new facility designed and built as part of the research project and the Future Model, which points to a blueprint for a HBPOS for the future.

2. Methodology

The project provides detailed analyses of patient journey in mental health crisis, based on a Grounded Theory Methodology and an Interpretative Phenomenological Analysis to examine research data. The overarching Grounded Theory identified a range of potential improvements, ranging from the issues with access to service and staff training to communication between stakeholders in the pathway. This presentation focused on the architectural intervention which was carried out during 2018–2019.

Semi-structured interviews and focus groups were conducted, which included patient, carer, clinician and London Metropolitan Police. The overall journey for mental health patients in the ED is complex, its facilities and built environments similarly relates to multiple considerations – functional, environmental, aesthetic, technological, medical, social and psychological. Through a carefully designed research framework, the research aimed to capture the fundamental and nuanced subjective views.

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[5] Bradley E. Karlin, Robert A Zeiss, “Best practices: Environmental and therapeutic issues in psychiatric hospital design: Toward best practices”. *Psychiatric Services* 57, 10 (2006), pp. 1376–1378; Paul B. Harris, Glen McBride, Chet Ross, Linnea Curtis, “A place to heal: Environmental sources of satisfaction among hospital patients”. *Journal of Applied Social Psychology* 32, 6 (2002), pp.1276–1299.

[6] Department of Health, *Mental Health Act 1983: Code of Practice*. Norwich 2015, pp. 139–152; Healthy London Partnership, *Mental Health*..., op. cit., pp. 26–48.

Participants were encouraged to sketch as well as talk about their personal experiences of the pathway, giving hermeneutic data which is not merely verbally descriptive but illustrative, intended to capture issues that may be missed in a verbal conversation. In addition, clinical data on the new facility is being gathered, which would include clinical incidents and the returning rate of frequent attenders, thus providing the empirical data for understanding the effect of the new facility.

3. The existing model: What is a health-based place of safety

Since 2010, active efforts have been made to address equality and aim to achieve parity of esteem between physical and mental health.[7] Among the legislative improvements was the introduction of a HBPOS to provide a suitable built environment for clinical assessment of individuals detained by the police under the MHA.

Despite the guidelines, Building Regulations and existing knowledge of what contributes to wellbeing, many patients continue to be placed in windowless, small and institutional-looking rooms with unsuitable lighting and inadequate sound insulation. This provision disregards our understanding that physical environment is a critical component of patient care.[8] The consequences of this are potentially harmful to patients in crisis and result in longer recovery times.[9]

A HBPOS could be the patient's home, a relative/friend's home (under Section 135 detention), a hospital ward or, if applicable, a police station.[10] In practice, however, the ED often becomes the place where individuals arrive. As such, it was necessary for a facility to have effective and appropriate guidelines and regulations, as demonstrated in the Quality Standards for Liaison Psychiatry Services Guideline (2017) from the Psychiatric Liaison Accreditation Network (PLAN) and the Mental Health Crisis Care for Londoners (2017).

At the start of this research, a survey of the existing facilities, review of current guidelines and Building Regulations and site visits to similar facilities in London were carried out. The facility in Charing Cross Hospital consisted of a single room,

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[7] Department of Health and Social Care, *No Health Without Mental Health: A Cross--Government Mental Health Outcomes Strategy for People of All Ages*. London 2011, pp. 64–67.

[8] Harris et al., "A place...", op. cit., pp. 1276–1299; Karlin, Zeiss, "Best practices...," op. cit., pp. 1376–1378.

[9] The Royal College of Emergency Medicine, *Mental Health in Emergency Departments. A Toolkit for Improving Care*. Available at: https://www.rcem.ac.uk/docs/RCEM_Guidance/Mental_Health_Toolkit_2017.pdf (accessed 12.11.2019); Emma Whicher, *Transforming London's Mental Health Crisis Care Services*. Available at: https://www.england.nhs.uk/blog/emma-whicher/ (accessed 03.11.2019).

[10] Department of Health, *Mental Health...*, op. cit., pp. 139–152.

adjacent to the resuscitation bay and the London Ambulance Service entrance. This pointed to clear noise, privacy and disturbance issues, even though the adjacency to the resuscitation bay has proven to be convenient in incidents where patients have required urgent medical assistance. The single room also lacks flexibility and limits the availability to patients.

Architecturally, the room was finished in neutral decor with fixed, modular, blue vinyl seats and a plywood finished corner table. The furnishing was minimal, such that cushions and blankets were absent from the room, to keep patients and staff from harm. The walls were bare and finished with brilliant white paint, with fixed standard ceiling tiles forming a solid ceiling. The floor to ceiling height was generous and was measured at three metres. The observation window looks out directly to the ambulance entrance corridor, with no blinds or any means of privacy protection. The lighting was direct and sharp, made out of four T8, 18 watt 600 × 600 mm modular fluorescent fittings, with no means of dimming. The ambient noise level in the room was high, measured between 50–55 dB (equivalent to a noisy cafe), and the noise of ceiling ventilation is audible.

Under the current assessment criteria, the old facility would not qualify as a HBPOS, because it lacks an ensuite toilet and one of the two access doors was inaccessible. Otherwise, despite the glaring architectural deficiencies, the facility would have qualified for the status. Notwithstanding the fact of accreditation, in Charing Cross Hospital and elsewhere, the existing facilities would have been used for all patients presented with mental health crisis, including those held under the MHA.

Research in environmental psychology is well established across disciplines, yet little research has been done on suitable environments for patients with mental health disorders.[11] This is the case in both medical and architectural fields – particularly for mental health patients in urgent and emergency care settings. A systematic review was carried out to understand the validity of the research. In addition, a review of existing building guidelines was undertaken. The study found that, in general, similar facilities present common issues and that, in terms of architectural and design guidance, the PLAN Standards can be improved upon.

For example, the Standards state the importance of patients' psychological, social and communication need in clinical assessments in the ED. In terms of the specifications for the built environment, however, the document does not extend such ambition in its requirement for the built environment. Space is not neutral; it carries with it a psychological and social relationship with its

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[11] Mardelle McCuskey Shepley, Angela Watson, Francis Pitts, Anne Garrity, Elizabeth Spelman, Janhawi Kelkar, Andrea Fronsman, "Mental and behavioral health environments: Critical considerations for facility design". *General Hospital Psychiatry* 42 (2016), pp. 15–21.

occupants. Furthermore, the Standards do not provide guidance on the sizes of the patient room, the level of lighting, the requirement of acoustic insulation, degree of privacy, nor an aspiration for natural light or an intent to actively promote better design. Yet such building guidelines exist elsewhere in wider Building Regulations. The primary concern in the existing Standards for the built environment is the physical safety of patients.

The physical safety of staff and patients is of paramount importance, however, an appropriate balance between safety and wellbeing should and can be found by having regard for both. Research showed improvements on the built environment reduce aggression and stress level,[12] which could in turn minimise the risk of harm and damage. Only 12% of service users felt the current rooms were pleasant, comfortable or welcoming.[13] The lack of specificity on providing basic level of comfort should incentivise designers and commissioners of ED to raise the standards.

Architects ought to be a guiding force in implementing environmental improvements and implementing designs to achieve better clinical outcomes. The National Minimum Standards for psychiatric care[14] (NAPICU 2014) and relevant guidelines promote a patient-centred and recovery focused care for patients with mental health disorders. In the context of the ED, more could be done to ensure the built environment matches such patient and recovery focused ethos in clinical care.

4. The present model: a place of safety in Charing Cross Hospital

With regard to an effective built environment for patients in mental health crisis, the topics explored and addressed in the course of the research included the overall planning of the ED, provision of space for mental health patients, reinforcement of security, upgrade of acoustic insulation and design of internal fit-out. This presentation concentrates the discussion on lighting and how it assisted with patient care and improved healthcare outcomes.

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[12] Roger S. Ulrich, Craig Zimring, Xiaobo Quan, Anjali Joseph, "The environment's impact on stress". In: Sara Marberry (ed.), *Improving Healthcare with Better Building Design*. Chicago 2006, pp. 37–61; Design Council, *Reducing Violence and Aggression in A&E*. Available at: https://www.designcouncil.org.uk/sites/default/files/asset/document/ReducingViolenceAndAggressionInAandE.pdf (accessed 11.11.2019).

[13] Healthy London Partnership, *Health Based Place of Safety: Business Case*. Available at: https://www.healthylondon.org/wp-content/uploads/2018/04/Business-Case-Crisis-Care-April-2018.pdf (accessed 03.10.2019).

[14] National Association of Psychiatric Intensive Care Unit, *Design Guidance for Psychiatric Intensive Care Units*. Available at: https://napicu.org.uk/wp-content/uploads/2017/05/Design-Guidance-for-Psychiatric-Intensive-Care-Units-2017.pdf (accessed 11.11.2019).

The proposed lighting scheme utilised technology and the understanding of the effect of lighting to address issues common in mental health patient facilities in the ED: the inability to tell the time of day, the lack of connection to natural light and the lack of stimuli, which all contributed to a dehumanised environment. The lighting design addressed three main areas:

1) enhance the perception of the built environment,
2) maintain patients' circadian rhythm,
3) induce behaviour change.

4.1. The environmental perception

The physiological and psychological effect of light is well understood. Seasonal Affective Disorder affects approximately 5% of people exposed to shorter hours of daylight, who suffer sadness, fatigue and depression.[15] Exposure to light helps the human body to regulate the production of melatonin, which in turn helps to regulate our body clock, affecting sleep patterns and digestion. Visible light also helps to stimulate the body's production of serotonin, a neurotransmitter which can reduce the symptoms of depression.[16] Such knowledge should be better applied to the built environments for patients, utilising both natural and artificial light.

Study has also found that the average length of stay for psychiatric inpatients in brightly lit rooms to be shorter, compared to those who are in dull rooms.[17] Despite this, under current guidelines, having natural light is not a requirement for a mental health patient facility in the ED.

Commercially available lighting products claiming to be "full spectrum" are available but cannot fully emulate daylight, and there is currently no industry standard for such claim. As a result of this project, natural light was introduced into the new patient room with a 900 × 1100 mm safety window. It is hoped that the light, whilst indirect, can provide patients a sense of the world beyond, while allowing a degree of natural light to reach the room.

In addition to the introduction of daylight, the lighting strategy focused on evoking a sense of nature and a connection to the passing of time. This resulted in a lighting installation which displayed the film of nearby London sky. The installation spanned two metres, almost the width of the room, and was positioned

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[15] Gary W. Evans, "The built environment and mental health". *Journal of Urban Health* 80, 4 (2003), pp. 536–555.

[16] Simon N. Young, "How to increase serotonin in the human brain without drugs". *Journal of Psychiatry & Neuroscience* 32, 6 (2007), pp. 394–399.

[17] Kathleen M. Beauchemin, Peter Hays, "Sunny hospital rooms expedite recovery from severe and refractory depressions". *Journal of Affective Disorders* 40, 1–2 (1996), pp. 49–51.

above where patients would lie down, to enhance the perception and immersiveness of the imageries. The 1300 × 2000 mm light installation was a back-lit high output, low-resolution light box, looped with a 24-hour programme and control with the latest SPI technology.

The design decision was made to choose the low-resolution LED imagery rather than a standard high resolution TV screen, in an attempt to create a more abstract interpretation of the outside world. The result of the installation created a gentle abstraction to the films. The subtle ambiguity of the image helped to evoke the sense of natural sky, without attempting to imitate nature literally. It was hoped that the naturalistic and slow-moving film would act as a suggestive sensory stimulus and an environment that nudged positive behavioural change in patients.

Beyond the sensory light installation, an element of control was introduced into the space. Patients in the new facility had the option of dimming lights as well as turning off the light installation. Plain white light is available in two colour temperatures, allowing a softer light in the evening.

Overall, these design changes intended to encourage positive perception of the high-risk assessment room. The research is continuing to gather data to understand patient feedback.

4.2. The circadian rhythm

The research identified that mental health patients lose track of time in existing facilities. Some participants interviewed found their stay in the windowless environment disorientating, and clinicians in the hospital had specifically pointed out the absence of clocks in such facilities as an issue. In a high-risk mental health room, any fixtures on the walls are a potential ligature point and a safety concern. Whilst being crucial to safeguard such an environment, this again illustrates the disparity of concerns for the psychological wellbeing: the majority of mental health patients who suffer less severe illnesses and who would not display aggression but would appreciate the attention paid to their needs.

The project proposed a combination of design solutions, including an integrated digital clock, introduction of natural light and a "natural sky" lighting installation. All three interventions work as a whole to assist patients in a difficult period of their lives, by reinforcing the natural sleeping cycle.

Evidence has shown a connection between lighting and improved sleeping and circadian rhythm.[18] Although specific artificial lights are used in phototherapy

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[18] Eus J.W. Van Someren, Annemarieke Kessler, Majid Mirmiran, Dick F. Swaab, "Indirect bright light improves circadian rest-activity rhythm disturbances in demented patients". *Biological Psychiatry* 41, 9 (1997), pp. 955–963; Roger Ulrich, Xiaobo Quan, Craig Zimring,

and achieve higher lux than normal lamps, it should be noted, however, that artificial lighting can never emit the range of colour frequencies as the natural daylight,[19] even on a cloudy day, the light level outdoor can exceed 1000 lux, a level which cannot be easily replicated indoors. Thus, as discussed, one of the design priorities was the installation of a new window.

As much benefit as the new window in the room may provide, it is nonetheless restricted by its size and by the frosted privacy film, which further reduces light transmission. Furthermore, the amount of natural light is also dictated by the orientation of the room within the building, which in this case was north-westerly facing. This contradicted previous studies which pointed to benefits of morning light[20]. Architects are aware of the benefits of daylight, however, more studies can help to identify the amount of daylight appropriate in the clinical environment, a level that does not compromise patient wellbeing.

These shortcomings in the project could have been easily addressed in a newly built hospital or if there had been more strategic planning in the building design process from the start. However, this study responded to these limitations with a future proposal for external courtyard space, discussed later.

4.3. Behaviour change

Acute Behavioural Disturbance in the ED poses a serious risk to patients and staff and contributes to the general milieu of the rest of the department. By reducing violent episodes in high-risk mental health assessment room, the stress level and disruption for staff and other patients in the ED can be minimised.[21]

The link between lighting, the production of serotonin level and mood also informs us about the potential of influencing patient behaviour in such environments.[22] The light intervention intended to induce physiological and psychological connections with patients. Anxiety and aggression may be reduced by distracting

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Anjali Joseph, Ruchi Choudhary, *The Role of the Physical Environment in the Hospital of the 21st Century: A Once-in-a-lifetime Opportunity*. Available at: https://www.healthdesign.org/system/files/Ulrich_Role of Physical_2004.pdf (accessed 03.11.2019).

[19] Rensselaer Polytechnic Institute, *National Lighting Product Information Program*. Available at: https://www.lrc.rpi.edu/programs/nlpip/lightingAnswers/fullSpectrum/abstract.asp (accessed 24.11.2019).

[20] Jiuan Su Terman, Michael Terman, Ee-Sing Lo, Thomas B. Cooper, “Circadian time of morning light administration and therapeutic response in winter depression”. *Archives of General Psychiatry* 58, 1 (2001), pp. 69–75.

[21] Ulrich et al., “The environment’s...,” op. cit., pp. 37–61; Design Council, *Reducing Violence*, op. cit.

[22] Young, “How to increase...,” op. cit., pp. 394–399.

patients from a negative focus, as well as this physiological wellbeing could be enforced by regulating body clock, providing better sleep and lowering blood pressure, thus shift patient behaviour and ultimately assist recovery.

Based on the research so far, the feedback has been positive. Further studies and measures will be required to confirm behaviour changes and record any nuanced responses, if any, in the new room. After the patient room was in use, an incident was recorded where a patient was brought into the ED and placed in the new room. The patient displayed symptoms of anxiety, heart rate was taken; over the period of waiting in the room, the heart rate dropped from 140 bpm to 78 bpm.

The patient was recruited for an interview and at the light installation, the quietness and the general milieu of the room as a key calming factor in the pathway. The room is illustrated in the Mental Map in a disproportionate scale to other facilities. (Cf. Figure 1 below.)

The description and the drawing expressed the pivotal function the patient room served; quantified by the heart rate measurement. Had the participant's experience of the room been a negative one, would he or she be expressing the drawing in the same way?

5. Model of the future: next stage in Charing Cross Hospital ED and beyond

Whilst positive steps have been made to improve access to care, the future of mental health care in the ED continues to be a challenge against the growing demand, limited funding and the legacy of disparity.[23] Future stages of the research aim to engage more patients and allow the qualitative research to capture user perception of both old and new facilities, thus allowing a comparative understanding of the different mental health rooms which could inform future development of similar facilities.

The combination of improvements to the high-risk patient room included: acoustic, furniture, colour, material as well as the lighting design. Thus, whilst a positive feedback has been recorded, the effect of the light installation cannot be isolated. Further measures are being carried out to understand whether there are changes to the recovery rate, aggression level, length of stay and readmission rate. Further research shall be designed to understand the environmental elements which contributes to these changes. Should positive changes be experienced by patients, this can be an invaluable contribution for patients and help to relieve the pressure in ED and encourage the built environment to become a positive influencing factor in patients' clinical journeys.

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[23] NHS Confederation, *Time to Deliver. NHS Priorities for the New Government*. Available at: https://www.nhsconfed.org/resources/2019/12/time-to-deliver (accessed 21.10.2019).

As the research demonstrated, the ideal pathway for mental health patients in crisis is not in the ED. The busy environment does not lend itself to psychological recovery. However, patients can arrive in the ED with complex symptoms and with physical as well as psychological ill-health. In terms of access to care for patients in mental health crisis, the ED will continue to represent a crucial part of patient journey.

Architecture and the built environment are only part of the overall patient journey, the research discussed and implemented a range of service improvements as it recognised the importance of a holistic vision. We aim for the project to instigate further changes in the health system, not simply as a case study of the built environment, but a way of collaborative working that delivers a holistic improvement in a patient pathway.

Weekly meetings focused on mental health care in the ED are ongoing and engage a multidisciplinary group to inform the future pathway for patients with mental disorders. Apart from facilitating the research to implement the design of the high-risk patient room, such endeavours include the work to coordinate Frequent Attenders and address homelessness in the borough; trialling a Psychiatric Emergency Team Call for all patients presenting with the police under the MHA; and producing HEE funded training video for the Section 136 pathway. Such close collaboration shall be an ideal model for instigating change in all healthcare projects, as it instigates a holistic and systematic interventions that effectively improve care outcomes. This is especially true in emergency care for mental health patients, where the patient pathway is often complex and involve multiple sectors.

In terms of the built environment, the future facility for mental health patients in the ED extends its physical boundary into nature. No longer are patients confined to the traditionally windowless and dehumanised environment. The future phase of the project seeks to extend the facility into a protected courtyard, adjacent to the high-risk patient room.

The environmental factor of nature has been found to enforce positive wellbeing and behaviour, it reduces stress and provides distractions.[24] The availability of space, natural light and fresh air are additional means to allow patient confined to the ED to find a sense of relief and experience the physiological benefits.

In addition, the proposal of an outdoor courtyard offers a practical dimension for addressing the high proportion of mental health patients who smoke. Despite the downward trend of smokers in the general public, the rate of smoking remains high for patients with serious mental illness. The correlation

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[24] Roger S. Ulrich, Robert F. Simons, Barbara D. Losito, Evelyn Fiorito, Mark A. Miles, Michael Zelson, "Stress recovery during exposure to natural and urban environments". *Journal of Environmental Psychology* 11, 3 (1991), pp. 201–230; Ulrich et al., *The Role*..., op. cit.

can be seen where 40.5% of adults with serious mental illness are smokers in England, more than twice the rate of the general population.[25] As such, smoking cessation advice and education is especially important for this patient group. Thus, not only does the outdoor place of safety provides a temporary sanctuary, it offers opportunities to address other complex social issues for this patient group.

6. Conclusion

As demonstrated in this paper, the clinical environment is not merely a passive space for medical intervention. On the contrary, it is an important part of the care delivery and has a direct impact on patients. Not only can it reduce length of stay and medication,[26] but also it translates to economic benefits for healthcare providers. In the 21st century, we ought to think beyond the provision of basic care and focus on the quality of provisions and effectiveness services.

The reality is, as a society we are still in a position where basic access to mental health crisis care is insufficient and equality between mental and physical health is still being fought for.[27] Progress is slow, but the social attitude and government policies towards mental health care have shifted over the last decade. The HBPOS is a reflection of such improvement in access and availability of facilities for mental health patients, notwithstanding the challenges ahead.

The new facility in Charing Cross Hospital addresses the increase in demand in the ED by providing dedicated spaces for mental health crisis care and allowing the design of the built environment to actively contribute to better healthcare outcomes. In terms of provision of light and nature, the proposal of an external courtyard may provide additional relief to patients on the emergency pathway and open up opportunities for further clinical interventions. The post-occupancy feedback of this study is still being gathered, but the initial phase of interviews and feedback have shown positive correlations.

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[25] Action on Smoking and Health, *High Rates of Smoking Among People with Serious Mental Health Conditions*. Available at: http://ash.org.uk/media-and-news/press-releases-media-and-news/high-rates-of-smoking-among-people-with-serious-mental-health-conditions/ (accessed 10.11.2019).

[26] Roger S. Ulrich, "How design impacts wellness". *The Healthcare Forum Journal* 35, 5 (1992), pp. 20–25; Beauchemin, Hays, "Sunny hospital...," op. cit., pp. 49–51.

[27] Department of Health and Social Care, *The Government's Response to the Five Year Forward View for Mental Health*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/582120/FYFV_mental_health__government_response.pdf (accessed 21.10.2019); Department of Health and Social Care, *No Health...*, op. cit., pp. 68–69.

This research demonstrated a patient-centred method of working that is collaborative and strengthen the interface between architectural design with clinical delivery. This method of working should be fundamental to commissioning and designing of all clinical environments.

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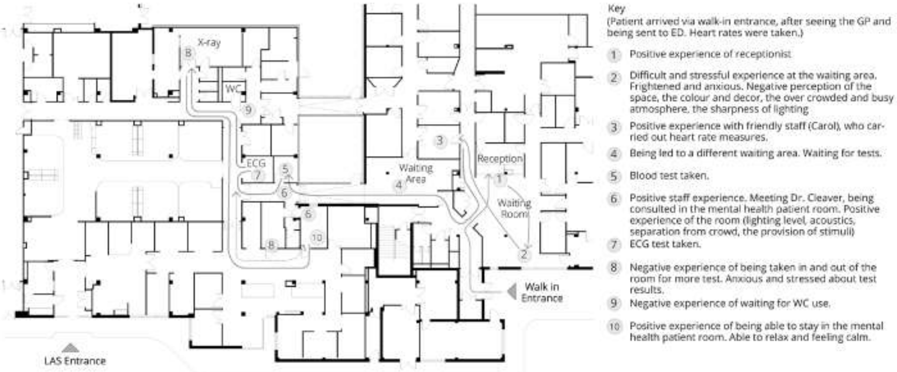
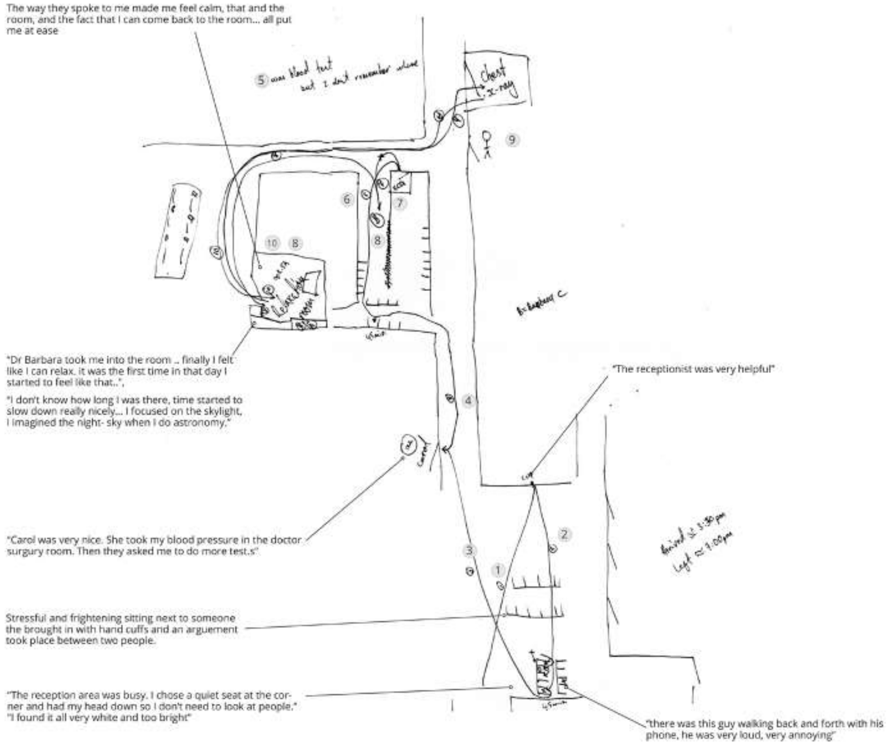


Key
(Patient arrived via walk-in entrance, after seeing the GP and being sent to ED. Heart rates were taken.)

1 Positive experience of receptionist
2 Difficult and stressful experience at the waiting area. Frightened and anxious. Negative perception of the space, the colour and decor, the over crowded and busy atmosphere, the sharpness of lighting
3 Positive experience with friendly staff (Carol), who carried out heart rate measures.
4 Being led to a different waiting area. Waiting for tests.
5 Blood test taken.
6 Positive staff experience. Meeting Dr. Cleaver, being consulted in the mental health patient room. Positive experience of the room (lighting level, acoustics, separation from crowd, the provision of stimuli)
7 ECG test taken.
8 Negative experience of being taken in and out of the room for more test. Anxious and stressed about test results.
9 Negative experience of waiting for WC use.
10 Positive experience of being able to stay in the mental health patient room. Able to relax and feeling calm.

Architectural Plan of Participant 3's Journey



The way they spoke to me made me feel calm, that and the room, and the fact that I can come back to the room... all put me at ease

"Dr Barbara took me into the room .. finally I felt like I can relax. it was the first time in that day I started to feel like that..",

"I don't know how long I was there, time started to slow down really nicely... I focused on the skylight, I imagined the night- sky when I do astronomy."

"The receptionist was very helpful"

"Carol was very nice. She took my blood pressure in the doctor surgury room. Then they asked me to do more test.s"

Stressful and frightening sitting next to someone the brought in with hand cuffs and an arguement took place between two people.

"The reception area was busy. I chose a quiet seat at the corner and had my head down so I don't need to look at people."
"I found it all very white and too bright"

"there was this guy walking back and forth with his phone, he was very loud, very annoying"

The Mental Map of Participant 3's Journey (paitnet's drawing)

Figure 1. The Architectural Plan and Mental Map

Figure 2. LED light installation in the new facility showing an evening (left) and daytime (right) view

Figure 3. Photographs of the old (left) and new facility (right)

Figure 4. Maintaining the Circadian Rhythm. The light installation is programmed to change over a 24-hour period, reproducing a natural daily cycle of light. It supports patients' natural circadian rhythms through naturalistic depiction of the sky

Ilhan Ilkilic

Ethical aspects of intercultural communication in the context of access to healthcare[1]

1. Introduction

Encounters between doctors and patients with different cultural backgrounds are part of daily practice in healthcare systems of several European countries. In these encounters, culturally shaped beliefs and values can lead to a different understanding of the key terms "health" and "illness". It is therefore common to experience divergent assessments of medical interventions in intercultural treatment situations in hospitals as well as in medical practices.[2] These differences often give rise to ethical conflicts and new challenges for medical decision-making processes in the healthcare system of a value pluralistic society.[3]

In some European countries, people with a migration background account for 20% of the population. For example, 20.8 million people with a migration background, representing 25.5% of the population, live in Germany.[4] Through the demographic changes in the number of migrants within the population, it can easily be foreseen that the number of doctor contacts with these people and their hospital stays due to aging will continuously increase over time. For instance, scientific studies on demographic changes show that, in Germany, around 2.8 million people with a migration background will be 60 years or older

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[1] This article has been published in *Zeitschrift für Medizinische Ethik* 65 (2019), pp. 425–435 in German. This is the revised and modified version of this article.

[2] Prerna Thaker, Ravi Rao, "Challenges faced by refugees to access health care in Germany". In: Florian Steger, Marcin Orzechowski, Giovanni Rubeis, Maximilian Schochow (eds.), *Migration and Medicine*. Freiburg, München 2000, pp. 253–271.

[3] Michael Coors, Tim Peters, Ilhan Ilkilic, "Kulturelle Differenz in der Gesundheitsversorgung". *Ethik in der Medizin* 30 (2018), pp. 177–179; Pranab Rudra, "Physician-patient relationship models in Bangladesh and Germany". In: Steger, Orzechowski, Rubeis, Schochow (eds.), *Migration*..., op. cit., pp. 87–104.

[4] Statistisches Bundesamt, *Bevölkerung. Migration und Integration*. Available at: https://www.destatis.de/DE/Presse/Pressemitteilungen/2019/08/PD19_314_12511.html;jsessionid=71FBD463A213D2020355BBAAF55B86F0.internet712 (accessed 01.06.2020).

in 2030.[5] Due to the increasing aging of people from other cultures, coupled with a corresponding increase in mortality in this population group, we have to deal with a continuously exacerbating problem both in clinical care and in normative-ethical decision making.

If we analyse everyday intercultural communication in hospitals and medical practices, we can find different problems not only of an organisational, but also ethical character.[6] Ethically appropriate solving of various conflicts which arise in the context of intercultural treatment situations requires successful communication. This article discusses the characteristics of interculturality treatment situations and analyses the ethical aspects of such communication. Based on this discussion, some ethical conflicts are pointed out and reflected upon.

2. Interculturality in treatment situations

The perception and experience of the stranger in daily medical life is very important for the emergence and shaping of interculturality in healthcare. In order to know what the stranger is, the philosopher Georg Stenger presupposes a horizon of understanding and a structure of order.[7] When interculturality arises, it is not only the foreign that is required, but also the subject that perceives the foreign. Because the perception of and experience with the stranger and their assessment as foreign is only possible by referring to one's own. The stranger's view and the difference between the "home world" (*Heimwelt*) and the "foreign world" (*Fremdwelt*) can be experienced relatively from the observer's perspective.[8] "Everything foreign is then foreign because it does not belong to the home world."[9] The German philos-

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[5] Statistisches Bundesamt, *Statistisches Jahrbuch 2007 für die Bundesrepublik Deutschland*. Wiesbaden 2007.

[6] Corinna Klingler, Georg Marckmann, "Difficulties experienced by migrant physicians working in German hospitals: A qualitative interview study". *Human Resources for Health* 14 (2016). Available at: https://doi.org/10.1186/s12960-016-0153-4; Ortrun Kliche, Sylvia Agbih, Ute Altains-Protzer, Corinna Klingler, Gerald Neitzke, Tim Peters, Michael Coors, "Ethische Aspekte des Dolmetschens im mehrsprachig-interkulturellen Arzt-Patienten-Verhältnis". *Ethik in der Medizin* 30 (2018), pp. 205–220; Giovanni Rubeis, "Mental healthcare in migrants from the perspective of public health ethics: Clinical factors, cultural diversity, and access barriers". In: Steger, Orzechowski, Rubeis, Schochow (eds.), *Migration*..., op. cit., pp. 31–46.

[7] Georg Stenger, *Philosophie der Interkulturalität: Erfahrung und Welten. Eine phänomenologische Studie*. Freiburg 2006, p. 354.

[8] Ibidem, p. 355.

[9] Ibidem. In German: "Alles Fremde ist dann deshalb fremd, weil es nicht zu diesem Eigenen der Heimwelt gehört."

opher Edmund Husserl described this strangeness and experience of others as "unknowns in the style of notoriety".[10]

The different contents of the terms "the stranger" and "the other" offer a helpful starting point for differentiating between the intercultural and intracultural context in healthcare. According to Stenger's differentiation, the focus is on a strong relational aspect with regard to the other. This strong relation arises between the own and the other through a common area of belonging. The assignment of the other can be represented in an intracultural relationship through common fields within one's own world.[11] The shared cultural and cultural-historical affiliation extends "from everyday life form and manners to language and non-verbal forms of communication, moral and moral conceptions to questions of historical origin and other more...".[12] In contrast, in an intercultural relationship dealing with strangers, some common areas are missing and thereby a strange world emerges.[13] Due to the lack of common cultural fields, the assignment of the foreign within the own world is difficult. "Otherness could always take place within the order, so to speak, 'strangeness' claims an 'outside'. [...] The 'stranger' is inevitably the step of a cultural transcensus."[14]

Based on the above-mentioned philosophical points, an intercultural doctor-patient/nurse-patient relationship includes an encounter in which an acting healthcare professional and a patient are involved as members of different "home worlds" or cultures. However, it is important to emphasise that belonging to different cultures and the associated interculturality arise from the context. This means that interculturality should not be defined by someone or even dictated from the outside. The intercultural context is to be determined by the subjects involved in this relationship and cannot be reduced to different skin colour, languages, nationality, religion, tradition, customs and ethnicity, etc. That is why every intercultural doctor-patient relationship – like every intracultural doctor-patient relationship – is unique. Its participants will shape this relationship as a process in a certain context.

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[10] Edmund Husserl, "Zur Phänomenologie der Intersubjektivität. Texte aus dem Nachlass. Dritter Teil: 1929–1935". In: *Edmund Husserl: Husserliana – Edmund Husserl. Gesammelte Werke*, Bd. XV. I. Kern (ed.). Dordrecht, Heidelberg 1973, p. 430, quoted by: Stenger, *Philosophie...*, op. cit., p. 355. In German: "Unbekanntheiten im Stil der Bekanntheiten."

[11] Stenger, *Philosophie...*, op. cit., p. 371.

[12] Ibidem, p. 374. In German: "von den alltäglichen Lebens- und Umgangsformen über Sprache und nonverbale Kommunikationsweisen, über Sitten- und Moralvorstellungen bis zu geschichtlichen Herkunftsfragen und andere[m] mehr..."

[13] Ibidem, p. 375.

[14] Ibidem, p. 377. In German: "'Andersheit' konnte sozusagen immer innerhalb der Ordnung Platz nehmen, 'Fremdheit' beansprucht ein 'Außerhalb'. [...] Mit dem 'Fremden' wird unweigerlich der Schritt eines Kulturtranszensus getan."

An intercultural context encompasses a temporal and physical space in which interculturality results from a relationship in the treatment situation. This intercultural context can arise in a close relationship, namely in the doctor/nurse–patient relationship or in another relationship where other participants such as patient relatives and members of the treatment team or hospital workers are involved. Patient relatives are not only family members of the patient, but also acquaintances and friends from his or her social environment. A pastor or religious adviser (e.g. an imam or rabbi) can also be part of such a relationship.[15]

Even though intercultural and intracultural treatment situations have many similarities in their essence, there are still significant differences of practical and ethical relevance. In these interactions, the lack of a collective language shapes both the perception and experience of the other as a stranger, which does not occur in intracultural treatment situations. Illness as an existential and exceptional experience is therefore connected with a certain speechlessness despite an interpreter. Furthermore, communication with the help of an interpreter impairs authentic communication. Culturally shaped subjective interpretation about the causes and genesis of diseases create numerous barriers in intracultural treatment situations. An essential reason for the existence of these barriers is the strangeness of such interpretation systems because, for various reasons, different values and thinking systems and the resulting values cannot be assigned to your own home world.

3. Intercultural communication in healthcare

Here, we understand, as intercultural communication, verbal, non-verbal and para-verbal forms of communication within the framework of intercultural treatment situations. This type of communication is by no means a special one, and therefore normally includes all the properties and problems discussed in the literature.[16] According to the expert in communication science, Gerhard Maletzke, we can speak about intercultural interaction and communication "if the encounter partners belong to different cultures and if the partners are aware of the fact that the other person is 'different', so if you are mutually experience as 'foreign'."[17]

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[15] Ilhan Ilkilic, Hakan Ertin, "Ethical conflicts in the treatment of fasting Muslim patients with diabetes during Ramadan". *Medicine, Health Care and Philosophy* 20 (2017), pp. 561–570.

[16] William B. Gudykunst, Bella Mody (eds.), *Handbook of International and Intercultural Communication*. Thousand Oaks 2002; Werner Nothdurft, "Art. Kommunikation". In: Jürgen Straub, Arne Weidemann, Doris Weidemann (eds.), *Handbuch interkulturelle Kommunikation und Kompetenz*. Stuttgart 2007, pp. 24–34.

[17] Gerhard Maletzke, *Interkulturelle Kommunikation*. Opladen 1996, p. 37. In German: „Wenn die Begegnungspartner verschiedenen Kulturen angehören und wenn sich die Partner der Tatsache bewusst sind, dass der jeweils andere 'anders' ist, wenn man sich also wechselseitig als 'fremd' erlebt."

In the literature, two forms of communication are distinguished from each other, namely the intercultural communication in the narrower sense and in the broader sense.[18] The first version includes all forms of communication between people who see themselves as belonging to different cultures, while the broad version of the same term (also) includes other forms of communication through different media such as film, television, radio, internet and others.[19] Even if the second type of communication in healthcare takes place occasionally, our focus here is primarily on the narrower version, i.e. face-to-face interaction. Here, the main focus is on the forms and character of language barriers and ethically relevant aspects in intercultural treatment situations.

A relationship between the participants will be established during the conversation between doctor, nurse or therapist and patient. Although not sufficient, a shared language is a necessary condition for the communication of complaints, wishes and interests. The whole treatment process is mainly based on this same language and thus maintains its inner structure. Understanding in dealing with each other seems to be a key problem. “Understanding at the same time conveys the prerequisites for any achievable and effective relationship between doctor and patient, namely trust and responsibility.”[20]

Communication in treatment situations certainly cannot be reduced to linguistic understanding.[21] The words used during the conversation have more functions than just reporting patient complaints and providing medical information about the diagnostic and therapeutic measures.[22] Thus, the cultural history and the cultural context of the words used within a treatment conversation convey more than just complaints, interests and wishes. “Sentences have a pre-logical history and they have a post-logical future.”[23] Not only does the language serve to present facts, but also opens up one’s own person. German medical anthropologist Fritz Hartmann describes such a conversation as revealing one’s own person and individual values.[24]

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[18] Edith Broszinsky-Schwabe, *Interkulturelle Kommunikation*. Wiesbaden 2011, p. 36.

[19] Volker Hinnenkamp, *Interkulturelle Kommunikation*. Heidelberg 1994, p. 5; Hans-Jürgen Lüsebrink, *Interkulturelle Kommunikation. Interaktion, Fremdwahrnehmung, Kulturtransfer*. Stuttgart 2005, p. 8; Broszinsky-Schwabe, *Interkulturelle*..., op. cit., p. 36.

[20] Fritz Hartmann, *Patient, Arzt und Medizin. Beiträge zur ärztlichen Anthropologie*. Göttingen 1984, p. 51. In German: “Verständigung vermittelt zugleich die Voraussetzungen jeder tragfähigen und wirksamen Beziehung von Arzt und Krankem, nämlich Vertrauen und Verantwortung.”

[21] Paul Lüth (ed.), *Kommunikation in der Medizin*. Stuttgart 1975; Thomas Ots, “Arzt-Patienten-Kommunikation und Krankheitsbegriff – Transkulturelle Erfahrungen”. In: Angelika Redder, Ingrid Wiese (eds.), *Medizinische Kommunikation*. Opladen 1994, pp. 30–43.

[22] Stenger, *Philosophie*..., op. cit., p. 355.

[23] Hartmann, *Patient*..., op. cit., p. 55. In German: “Sätze haben eine vorlogische Vorgeschichte und sie haben eine nachlogische Zukunft”.

[24] Ibidem, p. 62.

In this context, the lack of a common language in treatment situations plays an elementary role in the developing and shaping of interculturality. The lack of a common language means a communication situation where two parties cannot communicate in the same language. In such a situation, the physician as an expert who wants to meet a person's subjective need for help faces various difficulties.[25]

4. Forms of language barriers

The lack of a common language in a treatment situation occurs in different situations in medical practice. At least three forms are possible. In the first situation, the patient is unable to communicate in the language of the country, in which he or she lives. This situation is usually expressed in medical practice with the phrase: "He/she does not speak a word of English/German, etc". In such a situation, the necessary minimum understanding can only be guaranteed by consulting an interpreter. The quality and function of such communication depends mainly on the competence of the interpreter, which can vary a lot in practice.[26] As is known, this activity is performed not only by professional interpreters and colleagues in the treatment team, but also by family members or sometimes even by the cleaning staff.[27]

In the second situation, the patient can speak the language of the country, but his language skills are not sufficient for an appropriate communication. This enables elementary communication about current symptoms and the facts, but this language ability is not sufficient for a differentiated and constructive conversation. Unlike in the first situation, during such a conversation the doctor has the possibility of access to the patient's authentic complaints and individual value system. By using control questions, he can also check whether the information conveyed has been understood. If the doctor is convinced that the patient's language skills are not sufficient for the required conversation, he can – or should – use the help of an interpreter.

The third situation can be assessed by a good to very good language skills of the patient as a non-native speaker. An interpreter in such situations is usually not required, and a dedicated doctor-patient conversation can be shaped without

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[25] Karl Eduard Rothschuh, "Der Krankheitsbegriff". In: idem (ed.), *Was ist Krankheit?* Darmstadt 1975, pp. 397–420.

[26] Marlene Posner-Landsch, "Kommunikationsstörungen zwischen ausländischen Patientinnen und einheimischen Ärzten/Ärztinnen". In: Theda Borde, Matthias David (eds.), *Migration und Gesundheit. Zustandsbeschreibung und Zukunftsmodelle*. Frankfurt am Main 1998, pp. 59–79.

[27] Michael Gommel, "Interkulturelle Konflikte". In: Christian Hick (ed.), *Klinische Ethik*. Berlin 2007, pp. 197–205.

language barriers. However, further language specific semantic barriers in such communication processes cannot be ruled out, but they can be minimised with the necessary openness. Thereby, it is possible to create an access to the patient's own arguments for his or her decisions. Such open language communication would make an important contribution to clarifying the current character of interculturality and to a transparency of the values at stake. In this way, the normative meaning of interculturality can be better specified and understood.

In addition to the mentioned forms of language barriers, the context and character of language communication is also important. If it is only about a description of the symptoms (beginning, duration and location of the complaint) or instructions for taking medication (three times a day after meals, etc.) in a doctor/nurse-patient relationship, a person with lesser language skills can also help in such situations. On the other hand, the same language skills of the interpreter would not be sufficient to inform the patient about a complicated medical measure (e.g. a heart operation or organ transplantation). Not only better language skills are required for such complicated situations, but also knowledge on some medical terms and the ability to adequately convey the complex medical situation are needed. In these situations, the expectations of an interpreter's performance would be significantly higher.

5. Required skills of the interpreter in intercultural treatment situations

In an intercultural context in which the doctor and the patient do not speak the same language, the lack of a common language affects the necessary communication process. In order to overcome this language barrier, it is often necessary to involve a third person in the doctor-patient relationship. However, the occupation of an interpreter poses further problems with different qualities. Due to insufficient organisational and financial resources in many European countries, not trained, semi- or unprofessional people mostly improvise the job of interpreting. They are generally patient relatives, nurses and cleaning staff.[28] Unfortunately, such practices do not reach the required quality standards and include numerous ethical problems.

In intercultural communication processes, the interpreter has a special function and responsible duty. The quality of understanding of the moral value system and decisions depend on his performance. Again, this difficult task is associated with several challenges. The interpreter's work is initially connected with the well-known classic semantic and linguistic difficulties of every interpreting job. The communication barriers in an ethical conflict require additional

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[28] Matthias David, Ilhan Ilkilic, "Religiöser Glaube – Islam. Mögliche Konflikte im klinisch--gynäkologischen Alltag". *Der Gynäkologe* 43 (2010), pp. 53–57.

sensitivity in explaining the foreign moral beliefs and their justifications among the involved parties. The forwarding of morally relevant terms and contents in an appropriate way is also a very complicated matter. If the choice of words is wrong or if the meaning is not conveyed, a talk at cross-purposes is pre-programmed. For this reason, in addition to the necessary language skills, interpreting in the context of clinical ethics advice requires moral sensitivity and cultural competence.[29] Clearly, not every hospital employee or even professional interpreter can meet these high standards.

A further challenge with interpreting lies in the non-verbal level, which includes an appropriate and correct interpretation of the gestures, facial expressions and posture of the patient.[30] These can provide the treatment team with important clues about the patient's attitude to certain topics and medical interventions.[31] The interpreter should understand these messages correctly, which requires additional sensitivity: a sensitive attitude, sufficient knowledge of the meaning of these attitudes and sufficient experience in such communication situations are required. Due to such challenges, experts are convinced that interpreters should not only be *bilingual*, but also *bicultural*.[32]

There is a great deal of literature and many advanced training courses on information and interpretation of gestures, facial expressions and posture. In these courses, the meanings of these behaviours are described and certain procedures are recommended. However, it should be emphasised that this information and tips should not be used without reflection. These recommendations may only be used after a critical review and after verification through verbal communication. Especially in a diaspora situation, typical cultural behaviours in such circumstances are easy to influence. Furthermore, a critical handling of this information and recommendations is an essential part of a reflected cultural sensitivity.

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[29] Ilhan Ilkilic, "Interkulturelle Kompetenz. Schlüsselqualifikation in einer kosmopolitischen Medizin?" In: Andreas Frewer, Lutz Bergemann, Caroline Hack, Hans G. Ulrich (eds.), *Die kosmopolitische Klinik. Globalisierung und kultursensible Medizin*. Würzburg 2017, pp. 129–146.

[30] Peter A. Andersen, "Nonverbal communication across cultures". In: Gudykunst, Mody (eds.), *Handbook…*, op. cit., pp. 89–106; Dagmar Kumbier, Friedemann Schulz von Thun (eds.), *Interkulturelle Kommunikation: Methoden, Modelle, Beispiele*. Hamburg 2006; Alois Moosmüller, "Interkulturelle Kommunikation: Quo vadis?" In: Matthias Otten, Alexander Scheitza, Andrea Cnyrim (eds.), *Interkulturelle Kompetenz im Wandel*. Berlin 2009, pp. 41–56.

[31] Louise Bezuidenhout, Pascal Borry, "Examining the role of informal interpretation in medical interviews". *Journal of Medical Ethics* 35 (2009), pp. 159–162.

[32] Mary Snell-Hornby, "Übersetzen". In: Straub, Weidemann, Weidemann (eds.), *Handbuch…*, op. cit., pp. 86–94.

6. Filtering and censoring of information through patient family members as an ethical problem

Even if the topic of communication is not one of the classical topics in medical ethics, it should not be forgotten that the patient's information with regard to informed consent always has an ethical dimension. Not every patient's information has always an ethical conflict, but due to inappropriate communication with the patient it would cause ethical and legal problems.[33] For the legal and ethical validity of the patient's consent, the doctor needs to provide the patient with information appropriately. If this information is not adequate due to language barriers, the patient's consent is not valid. This means that ethical legitimacy and legal justification of the patient's information depends on the good performance of the interpreter. This shows that the lack of the interpreter's skills described above is always associated with an ethical problem.

In addition to the difficulties in realising adequate linguistic communication mentioned above, it is not uncommon that the patient's family members who act as interpreters change the doctor's statements. In practice, numerous cases are known in which the participants cannot communicate in their native language and linguistic communication is filtered, censored or interpreted for various reasons. Not only the lack of language skills, but also the lack of neutrality during interpreting can lead to incorrect interpretation. Due to the differing moral convictions, it is not uncommon for an interpreting family member to withhold a bad diagnosis and prognosis from the patient, in order not to impair the patient's wellbeing. Because interpretation deficits cannot be identified or checked by the doctor, the necessary patient information and the associated self-determined consent of the patient cannot be adequately guaranteed. These ethical conflicts are substantiated here by using a case study and ethically reflected in the discussion.

6.1. Case

A 23-year-old Turkish man was diagnosed with malignant cancer in a German hospital. Several cycles of chemotherapy achieved no success in treatment. The patient's state of health deteriorated progressively, making his imminent death more and more likely. The patient was transferred to a palliative ward. Both the patient and his parents had only rudimentary knowledge of the German language, which did not allow an adequate communication with the medical team. With the help of an interpreter, who was a member of their wider family,

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[33] Kurt W. Schmidt, Gabriele Wolfslast, "Patientenaufklärung – Ethische und rechtliche Aspekte". *Deutsche Medizinische Wochenschrift* 127 (2002), pp. 634–637.

the doctor in charge informed the parents about their son's hopeless situation; the son was also partly involved in this talk.

A nurse of Turkish descent happened to overhear the conversation and later informed the doctors that the interpreter had not passed on to the patient the information about his expected imminent death, probably at the request of his parents. The doctors considered this a clear contravention of the patient's "right to know". With the help of a different interpreter, they arranged another conversation with the patient, during which he was informed of the possibility that he might soon die. Two days later the patient passed away. The parents later accused the doctors of being responsible for their son's death: they had contributed to the worsening of his condition and thus hastened his demise.

7. Discussion[34]

Here, there is a conflict between the patient's parents and the medical team regarding disclosure to the patient of an unfavourable diagnosis and prognosis. In this ethical conflict, the medical team believes that the patient himself or herself should decide whether they receive the full information about their condition. The patient himself or herself should decide between the *right to know* and the *right not to know*. In the medical team's decision-making process, autonomy gets the highest priority among other ethical principles. As an adult and autonomous human being, the patient should decide, through an individual evaluation of his various options. Withholding requisite information would mean disenfranchising the patient and violating his right to self-determination.

The starting point for the parents' decision and attitude is, however, a different one. Their approach may be described as caring and consequentialist. In their decision-making process, patient autonomy does not play a central role. For the parents, the issue is primarily whether the disclosure of the infaust prognosis will affect their son's wellbeing. They expect that the medical team's course of action will upset their son and thus weaken his regenerative powers. This approach is regarded as harmful in reference to one of withholding the diagnosis and prognosis. In this case, the patient died two days after receiving the information. His parents therefore felt that their decision had been vindicated, and they accused the medical team of having acted wrongly.

It is important to emphasise that the parents' attitudes such as those in the described case are widespread in many countries – including Turkey – and

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[34] For a differentiated commentary on this case cf. Ilhan Ilkilic, "Culture and ethical aspects of truth-telling in a value pluralistic society". In: Wansa Teays, Alison Dundes Renteln (eds.), *Global Bioethics and Human Rights. Contemporary Perspectives*. Lanham 2020, pp. 37–50.

are based predominantly on traditional moral convictions.[35] In many countries, it is not unusual to speak with the attending physician, usually before the diagnosis, and to express a wish not to inform the patient about a bad diagnosis. After the diagnosis it is also common for the attending doctor to first discuss further medical procedure with the patient's relatives.[36]

The described case occurred in Germany. The parents' wish is not easy realisable in practice because of legal reasons and the physicians' common ethos. These facts make the case complicated and it is a challenge for a value pluralistic society. The medical team is in a dilemma between the legal circumstances and the culture-related behaviour as well as the wishes of the patient's parents. At the ethical level, we find here the classical question of ethics, namely whether the medical ethical principles such as respect for patient autonomy can claim an egalitarian validity? Can we ascribe this ethical principle as being universally binding?[37]

8. Conclusions

While the doctor informs the patient about diagnostics and necessary therapeutic measures, the patient clarifies the doctor about his complaints, wishes and preferences. Successful communication is therefore not only important for communicating patient complaints and medical instructions, but it is also essential for getting access to the patient's value system and preferences. As described above, this elementary understanding is impaired, for various reasons, in intercultural treatment situations. Since medical treatment is only ethically justified with the patient's informed consent, these types of impairments in intercultural health care should not be considered as unimportant. Trying to remove these language barriers with the help of hospital interpreting services, in which semi-professional volunteer hospital staff work, often does not meet the required

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[35] Alan Jotkowitz, Simon Glick, Benni Gezundheit, "Truth-telling in a culturally diverse world". *Cancer Investigation* 24 (2006), pp. 786–789; Jefrey T. Berger, "Culture and ethnicity in clinical care". *Archives of Internal Medicine* 158 (1998), pp. 2085–2090; Marjorie Kagawa-Singer, Leslie. J. Blackhall, "Negotiating cross-cultural issues at the end of life". *The Journal of the American Medical Association* 286 (2001), pp. 2993–3001; Subrata Chattopadhyay, Alfred Simon, "East meets West: Cross-cultural perspective in end-of-life decision making from Indian and German viewpoints". *Medicine, Health Care, and Philosophy* 11 (2008), pp. 165–174.

[36] Leyla İyilikçi, "Practices of anaesthesiologists with regard to withholding and withdrawal of life support from the critically ill in Turkey". *Acta Anaesthesiologica Scandinavica* 48 (2004), pp. 457–462.

[37] Dieter Birnbacher, "Das Dilemma des bioethischen Pluralismus". In: Eva Baumann, Alexander Brink, Arnd T. May, Peter Schröder, Corinna Iris Schutzeichel (eds.), *Weltanschauliche Offenheit in der Bioethik*. Berlin 2004, pp. 51–64.

quality standards. The same situation is more problematic when interpreting is improvised by non-professional patient members, which can imply some filtering and changing of the patient's conversation. It cannot be ruled out that an authority relationship between the patient and the family member acting as interpreter jeopardises authentic communication. A use-oriented professional service in intercultural communication situations could minimise or solve such ethical problems. Unfortunately, despite the great practical need in many healthcare systems of several European countries, it has not yet been established. Even if the continued accessibility of such services is associated with numerous structural problems and organisational challenges and requires financial resources, there are good ethical reasons for establishing these services across the board or at least improving the current situation.

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Simona Mlinar

Access to health care from the aspect of the Human Rights Ombudsman of the Republic of Slovenia

1. Introduction

In the present paper, I present the work of the Human Rights Ombudsman of the Republic of Slovenia (hereinafter: Ombudsman) related to tackling problems of individuals who wish to enforce their rights in the healthcare system in the Republic of Slovenia. The Ombudsman deals mostly with individual cases. These cases, which within the Ombudsman's office are called complaints, often show legal deficiencies and the rigidity of the healthcare system, which implies consequences in the access to healthcare.

I present four practical cases of the Ombudsman in healthcare relating to affected individuals and healthcare staff. First, I present the legal basis enabling the Ombudsman to consider complaints of individuals, and legal basis that determines the right to healthcare in the Republic of Slovenia, which are most frequently tackled by the Ombudsman. The Ombudsman is a constitutional category and is not categorised under the executive or judicial or legislative branches of power. In relation to other national authorities, the Ombudsman is an independent and autonomous body. The Ombudsman has powers with regard to all state authorities, local self-government bodies and holders of public authority.

In accordance with Article 23 of the Human Rights Ombudsman Act, the "Ombudsman has certain powers with regard to all state authorities, local self-government bodies and holders of public authority". Article 9 of the Act stipulates that "anyone who believes that their human rights or fundamental freedoms have been violated by an act of an authority may file a complaint to initiate proceedings with the Ombudsman. The Ombudsman may also instigate proceedings of their own accord."[1]

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[1] Human Rights Ombudsman Act [Zakon o varuhu človekovih pravic]. *Official Gazette of the Republic of Slovenia*, No. 69/17.

In 2018, the Ombudsman examined 3073 complaints; 2661 of them were completed and 412 are still being processed. 398 complaints, or 15% of all complaints, were founded (meaning that the Ombudsman found that the claims of complainants on the violation of human rights and fundamental freedoms were well-founded), 541 of them were not founded, 1423 contained no content for consideration (meaning that there were legal proceedings in progress where no delay or major irregularities were found, including anonymous complaints, tardy complaints, insulting complaints and complaints where proceedings were discontinued because of complaint withdrawal or the lack of collaboration of the complainant); 229 of them were outside the Ombudsman's jurisdiction. 231 complaints were considered as related to healthcare; 47 of them were related to health insurance (this mostly involves procedures connected with rights arising from health insurance processed by the Health Insurance Institute of Slovenia), and 184 of them were related to healthcare (complaints by patients against health care services providers, complaints by providers, system irregularities concerning health care regulation, etc.).[2]

The right to healthcare is determined in Article 51 of the Constitution of the Republic of Slovenia: "Everyone has the right to healthcare under conditions provided by law. The rights to healthcare from public funds shall be provided by law".[3] In the Republic of Slovenia, we have compulsory and voluntary supplementary health insurance. The basic feature of health insurance is that the rights of each individual or dependent family members (e.g. children) are related to insurance registration and the payment of an appropriate compulsory health insurance contribution or voluntary health insurance premium. The fundamental law determining the rights of individuals to health care is the Health Care and Health Insurance Act (hereinafter: ZZVZZ). Twenty-five points of Article 15 refer to insured persons. Health insurance in Slovenia is compulsory for everyone meeting the statutory requirements as determined in the ZZVZZ. These are individuals who have to hold compulsory health insurance with regard to their status. The right to healthcare depends on whether a person fulfils the conditions for inclusion in the compulsory health insurance. This means that an insured person cannot choose whether they are insured or not, and insurance cannot be autonomously terminated. Debt arises in case of non-payment. If the debt is not settled, the individual's access to the rights from health insurance is disabled.

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[2] Human Rights Ombudsman of the Republic of Slovenia, *The 24th Annual Report of the Human Rights Ombudsman of the Republic of Slovenia for 2018*. Ljubljana 2019.

[3] Constitution of the Republic of Slovenia [Ustava Republike Slovenije]. *Official Gazette of the Republic of Slovenia*, Nos. 33/91-I, 42/97 – UZS68, 66/00 – UZ80, 24/03 – UZ3a, 47, 68, 69/04 – UZ14, 69/04 – UZ43, 69/04 – UZ50, 68/06 – UZ121, 140, 143, 47/13 – UZ148, 47/13 – UZ90, 97, 99, 75/16 – UZ70a and 92/21 – UZ62a.

2. Methodology

I analyse four cases with regard to the Ombudsman's competences, which were examined by the Ombudsman:

1) problems with healthcare provision for the Roma,
2) death of a Macedonian citizen,
3) problems with healthcare provision to an applicant for international protection, and
4) problems with healthcare provision to a person under international protection.

I have selected the cases with regard to the problem area. The key search terms included: healthcare, migrants, the Roma, asylum applicants, international protection applicants, aliens. The cases mostly highlight the problems detected by the Ombudsman while examining those cases. I present some systemic problems related to the enforcement of rights to healthcare in the Republic of Slovenia.

3. Results

3.1. Problems with healthcare provision for the Roma (2011)

A complainant wrote to the Ombudsman about problems when arranging permanent residence.[4] Why is this relevant for healthcare? Since the complainant did not have permanent residence, she was not able to register in the health insurance system. When writing to the Ombudsman, the complainant was nine months pregnant with her third child. She claimed that she was a citizen of the Republic of Slovenia and living in the Roma settlement in area (A). Her last permanent residence was arranged in place (B). She received financial social aid from the social work centre (B). When verifying the permanent residence, the administrative unit of place (B) established that the complainant was no longer living where she was registered. Therefore, the administrative unit deregistered her address of permanent residence. The complainant lived in Croatia, where her residential status was not arranged. The complainant returned to Slovenia because she was deported from Croatia. She was deported because she entered the territory of the Republic of Croatia before her preliminary prohibition of entry had expired. She returned to Slovenia and moved in with her partner and his mother in the area of the municipality of place (A). She had no permanent residence. In accordance with Article 8 of the Act Amending the Residence Registration Act,[5] it was stipulated that if the individual has no residence and does not fulfil the terms for

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[4] Human Rights Ombudsman of the Republic of Slovenia, *Annual Report of the Human Rights Ombudsman of the Republic of Slovenia for 2011*. Ljubljana 2012.

[5] Act Amending the Residence Registration Act [Zakon o spremembah in dopolnitvah Zakona o prijavi prebivališča]. *Official Gazette of the Republic of Slovenia*, No. 36/21.

residence registration, the address of the authority (e.g. social work centre) or the organisation where the person obtains aid in material form, if they actually live in the area of the competent authority, shall be considered as permanent residence. The problem was that the complainant lived in an illegal Roma settlement, i.e. in a trailer, and it was therefore impossible to determine the number or register permanent residence due to her illegal residence. The complainant lived in the area of the municipality of place (A), but she did not receive any allowance from the social work centre (A). Therefore, the social work centre in place (A) could not register her at their address because she did not fulfil the condition of living and receiving assistance at the same time. A similar situation occurred in the area of municipality (B), where the complainant received her last financial social assistance from the social work centre (B) but she did not actually live there. Therefore, the social work centre in place (B) did not want to register permanent residence at their address because she did not live in their area.

The Ombudsman made several enquiries and held phone conservations with the social work centres from places (A) and (B), with administrative units of places (A) and (B) and with the Ministry of the Interior. Sending enquiries is a standard procedure and one of the methods the Ombudsman uses to establish the current situation. The Ombudsman found that the administrative unit (A) initiated the actual residence procedure. The administrative unit (A) was also prepared to arrange the registration of permanent residence to the complainant at the address of the social work centre in place (A) upon preliminary acquisition of a written consent of the social work centre in place (A). The written consent was necessary because the complainant did not fulfil both conditions for permanent residence registration. The Ombudsman asked the social work centre (A) to issue the consent as soon as possible and to execute the permanent residence registration procedure immediately so that the complainant could arrange health insurance for herself and her daughter.

The Ombudsman informed the competent authorities of its findings and the standpoint, i.e. that a systemic problem, the result of a vague regulation of the Residence Registration Act, had been detected. The complainant had problems with fulfilling both conditions for permanent residence registration (receiving assistance and residing in the area where the assistance is received). The bodies which are competent to establish and arrange permanent residence claimed that they do not have jurisdiction, which consequently violated the rights of individuals to arrange their permanent residence, which is also connected to other social rights. The social work centre in place (A) where the complainant resides, issued a consent for the registration of permanent residence in collaboration with the Ministry of the Interior. On the basis of the said case, the Ombudsman proposed to the Ministry of the Interior to consider our comments when passing new laws. The Ombudsman's comments were considered in the drafting of the new Residence Registration Act, which entered into force on 13 August 2016. This case clearly shows that one case is sufficient to show the anomaly of a certain system.

3.2. Death of a Macedonian citizen working in Slovenia (2010)

The second case describes a situation involving foreign workers who have not been registered in the health insurance system by their employers.[6] A Macedonian citizen temporarily working in Slovenia had chest pain when reporting at the emergency unit of a health clinic. During examination, the nurse performing triage explained to him that he had no health insurance and that there was a possibility that, if his health condition did not require emergency medical assistance, he would have to pay EUR 100. Emergency medical assistance and emergency treatment are covered by the state budget. The patient was not aware of not having any insurance and was angry with his employer who did not register him in the health insurance system. He decided not to have the examination. He left the emergency unit. The nurse was not informed of his departure. In a few hours he died at the hotel where he was residing. For better understanding, the terms of emergency medical assistance and emergency treatment are stipulated in Article 103 of the Rules on Compulsory Health Insurance (emergency medical assistance and emergency treatment). Emergency medical assistance includes resuscitation services, life-support services, services to prevent severe further deterioration of health of people who have suddenly fallen ill, suffered an injury or suffer from a chronic disease. The services are provided until life functions have been stabilised or until treatment is provided at the proper location. Emergency rescue transport is included within the context of emergency medical assistance services. Emergency treatment and medical services that cannot be postponed include the following:

- immediate treatment after the provision of emergency medical assistance, if necessary,
- wound dressing, prevention of sudden and fatal deterioration of chronic disease or medical condition that could cause permanent damage to individual organs or their functions,
- treatment of sprains and fractures, as well as injuries that require specialist treatment,
- treatment of poisoning,
- services to prevent the spread of infections which could cause septicaemia (sepsis) in the insured person,

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[6] Human Rights Ombudsman of the Republic of Slovenia, *Annual Report of the Human Rights Ombudsman of the Republic of Slovenia for 2010*. Ljubljana 2011.

- treatment of diseases whose treatment is compulsory by law or services that the law classifies as compulsory treatment and for which costs are not covered by the state, the employer or the insured person,
- medicinal products that are prescribed from the positive list and that are required to treat the conditions referred to in the previous indents,
- medical devices required to treat the conditions referred to in the previous indents, namely to the extent, standards and norms as set out in the rules.[7]

In connection to the mentioned case, the Ombudsman started their own examination of the case. We sent enquiries to the Ministry of Health, Labour Inspectorate of the Republic of Slovenia and the health clinic, and asked them to act accordingly.

Internal professional supervision at the health clinic did not find any irregularities in the subject's medical treatment. The latter was conducted in accordance with the internal instructions on treating a person who arrives at the emergency unit of the health clinic. The Labour Inspectorate of the Republic of Slovenia found many irregularities when examining the employer of the deceased worker; two months prior to the examination, the worker's employment relationship had been terminated, and the worker was "lent" to another employer, where the worker's social contributions were not paid. Therefore, he had no health insurance. He had no employment contract, no holiday pay, he worked unpaid overtime hours, had no weekly rest, leave, etc. The employer did not pay contributions for three other foreign workers, either.

The Ministry of Health emphasised that Slovenia offers unconditional emergency assistance to anyone who needs it, but emergency treatment services also have to be paid for. If the treatment is offered to a person who is entitled to emergency treatment, the service cost is paid to the medical services provider from the budget of the Republic of Slovenia.

The case showed that there are systemic problems connected with employing foreign workers. They often work illegally, and employers exploit them, and when they fall ill, they have no rights. The organisation of healthcare is of key importance because the nurse only respected the "house rules", which also implied the issue of competences and responsibilities. Problems that had already been highlighted by the Ombudsman in other cases also arose, i.e. that the patients themselves cannot judge the level of emergency of their health status. People without health insurance are thus forced to make such decisions because they have to assess whether to risk a potential payment for examination if it is proven that their condition could not be considered as urgent. The case also showed that

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[7] Article 103 on emergency medical assistance and emergency treatment, amending the Rules on compulsory health insurance [Spremembe in dopolnitve Pravil obveznega zdravstvenega zavarovanja]. *Official Gazette of the Republic of Slovenia*, No. 183/21.

people without health insurance have to be included in the healthcare system. The Ombudsman recommended to the Minister of Health that all representative bodies of countries the citizens of which are most frequently found in circumstances when they require medical care, but do not have health insurance, should be properly informed about emergency treatment.

3.3. Problems in healthcare provision to an international protection applicant (2014)

The third case relates to problems encountered by an international protection applicant after suffering a stroke while residing in the asylum centre.[8] Based on the authorisation of a male patient residing at the asylum centre who had suffered a stroke, a complainant wrote to the Ombudsman. The patient was treated at hospital and after treatment was discharged back to the asylum centre. The complainant informed the Ombudsman that after the concluded treatment, the patient did not get proper care and that a volunteer and other carers provided help to him. The patient had been showered only every fifth day and he had problems getting to the sanitary premises, and used a chamber pot. He was approved physical therapy (30 days, the costs were covered by the Ministry of Health); however, he had to make appointments with the physical therapist himself, which was impossible in his condition, since he could not move. The complainant wrote that the therapist was ill herself and claimed that there was nothing else she could do for the patient. He submitted an application for international protection, which was rejected.

As part of the examination, the Ombudsman visited the asylum centre. There, the Ombudsman found that the patient was getting physical therapy and medicines. The patient explained that in the first days after discharge from the hospital he was cared by staff and subsequently by the residents of the asylum centre. He said that he was satisfied at the asylum centre at that time. He also wanted to get proper treatment at the health resort, which, however, was not approved. He expected the Ombudsman to check whether treatment at a health resort can be included under emergency treatment.

The Ombudsman checked the possibilities of treatment in the health resort and found that this right is provided to insured persons as per Article 15 of the Health Care and Health Insurance Act, and to their family members as per Article 20 of the Act. International protection applicants are only assured emergency medical assistance in accordance with Article 84 of the International Protection Act (the same as Article 103 of the Rules on Compulsory Health

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[8] Human Rights Ombudsman of the Republic of Slovenia, *Annual Report of the Human Rights Ombudsman of the Republic of Slovenia for 2014*. Ljubljana 2015.

Insurance), which does not include treatment at a health resort. Emergency treatment includes resuscitation services, life-support services and services to prevent a further severe deterioration of health. Emergency treatment services are provided until life functions have been stabilised or until treatment is provided at the proper location. Treatment at a health resort is an "upgrade" of treatment and is intended to restore working and functional abilities. The Ombudsman found that, with regard to legal provisions, the patient was not entitled to treatment at a health resort and was properly informed about it.

The example showed that the expectations of complainants often exceed the competences of the Ombudsman's work. It also showed that the care of patients after the completion of treatment is not properly regulated.

3.4. Language barriers in healthcare provision to a person under international protection (2013)

The last case is interesting especially from the aspect of the role of language, since it seems that we often forget about its importance when speaking about proper medical care.[9]

A medical practitioner from one of the health clinics, who was selected as personal medical practitioner by a person with international protection status, wrote to the Ombudsman. Her patient, who came from Yemen, only understood Arabic. The patient had a very low level of knowledge of Slovenian and English. Therefore, the medical practitioner used an online application – an internet translation tool from English to Arabic – to examine her. On the one hand, whether or not she understood the patient and her health condition was quite worrying for the doctor, while on the other hand, she was not sure whether the patient understood her instructions and explanations regarding diagnostics, treatment and therapy. Besides the issues dealt with by the doctor, the examination itself at the health clinic lasted from 30 to 60 minutes due to translating, causing the dissatisfaction of other patients. The doctor was aware that the Constitution of the Republic of Slovenia gives her the right to communicate in Slovene; on the other hand, she was obliged, in accordance with the Patient Rights Act, to offer proper, quality and safe medical care to the patient. She wrote in the complaint that she was not able and capable of offering safe medical care in the described circumstances.

To solve her and the patient's problem, before contacting the Ombudsman, the doctor sought help at the Ministry of the Interior. The Ministry explained that they are not competent for providing interpreters and translators in healthcare to

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[9] Human Rights Ombudsman of the Republic of Slovenia, *Annual Report of the Human Rights Ombudsman of the Republic of Slovenia for 2013*. Ljubljana 2014.

people with recognised international protection. The patient had refugee status and therefore had compulsory health insurance. Only applicants for international protection, if they do not understand the language, have the right to an interpreter. The Ministry provides information to people with international protection which is necessary to facilitate their integration with the environment (accommodation, financial support, social and health care, education, employment...). The latter is ensured by providing people with an international protection information brochure and by personal counselling. The patient also attended a Slovenian language course, but her knowledge of the language was insufficient for an examination by the doctor.

The doctor asked the Ombudsman for help through the provision of a translator. The Ombudsman explained that we cannot provide interpreting services. We recommended that she should contact the Legal Information Centre and Slovenian Philanthropy (a non-governmental organisation) which implements an assistance programme for applicants for international protection, aliens and people with international protection. The doctor did not contact the Ombudsman again. We conclude and hope that our explanations were of assistance to her.

4. Conclusion

In conclusion, I would like to emphasise three things:

- First, all these cases show that the problems related to accessing healthcare services most often originate from unregulated status, due to which individuals do not fulfil the conditions for inclusion in the health insurance system. Problems connected with inclusion in the health insurance system and with access to healthcare are connected with an individual's status regulation (residence, employment, disabled status, retired person, etc.). Therefore, it would be sensible to consider all proposals for resolving the problems relating to access to healthcare comprehensively and also in connection with other social rights.
- Second, people without health insurance remain a problem. Pro-bono clinics or clinics for people without health insurance are a short-term solution, since people can look for help when they have non-urgent health problems, but this is not a long-term solution. Such clinics also do not offer all specialist services and have no capacities to hospitalise patients.
- Third, institutions included in the status regulation procedure often have to be flexible and ambitious in regulating an individual's status. It is not enough for us to have a regulated health insurance system because such problems cannot be resolved partially, but we need a comprehensive, systemic approach to enable inclusion of individuals in health insurance. Furthermore, despite the regulated legal system and proper legal bases, there are problems in practice when providing and accessing healthcare to aliens, the Roma, applicants

for international protection/asylum, etc. Therefore, caution is needed in adopting legal bases because it has been proven many times that subsequent changes of laws can be difficult and lengthy.

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