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Social diversity and access to healthcare

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Mojca Ramšak, Paweł Łuków, Amir Muzur and
Florian Steger (Eds.)

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Social diversity and access to healthcare

Social diversity may affect health outcomes in situations when access to healthcare is limited for certain social groups. Although non-discriminatory access to healthcare services is one of the basic principles of medical ethics and health law, there are still debates regarding the implementation of this concept in practice. Barriers such as inadequate legal entitlements, language, different concepts of health and disease, socio-economic factors or attitudes of healthcare professionals can hinder equity in access to healthcare. The authors of contributions gathered in this volume analyze challenges in access to healthcare for various minority groups and propose possible solutions.

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Preface

This volume is the result of the European Union project »Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe«, which is being conducted within the framework of the Joint Research Programme ›Public Spaces: Culture and Integration in Europe‹ funded by the Humanities in the European Research Area (HERA) network and the European Commission.

This project focuses on the concept of diversity that includes aspects of ethnicity, religion, gender, and sexual orientation in the social context of healthcare viewed as a public space. The aim of this project is to generate systematic knowledge about how and to what degree the European norms and guidelines concerning diversity are implemented in national legal regulations in Germany, Slovenia, Croatia, and Poland and how they are realized in clinical practice in these countries. The project concentrates on the ethical, cultural, and normative aspects of integration and exclusion within the healthcare sector.

The project is being realized in cooperation of research institutions at four European universities: the Institute of the History, Philosophy and Ethics of Medicine at Ulm University (Germany), the Institute of History of Medicine at the Faculty of Medicine of the University of Ljubljana (Slovenia), the Department of Social Sciences and Medical Humanities at the Faculty of Medicine of the University of Rijeka (Croatia), and the Center for Bioethics and Biolaw at the Faculty of Philosophy of the University of Warsaw (Poland).

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Ljubljana, Warsaw, Rijeka, and Ulm
April 2022

Mojca Ramšak, Paweł Łuków,
Amir Muzur and Florian Steger

Mojca Ramšak, Paweł Łuków, Amir Muzur and Florian Steger

Introduction

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

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

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

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[1] Constitution of the World Health Organization. New York, 22.7.1946 (Off. Rec. Wld Hlth Org., 2, 100).

[2] Universal Declaration of Human Rights. Paris, United Nations General Assembly, 10.12.1948.

[3] International Covenant on Economic, Social and Cultural Rights, Article 12. Geneva, Switzerland: United Nations Human Rights Office.

ing this right through international declarations, domestic legislation and policies, and at international conferences.«[4]

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

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

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

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

[5] World Health Organization: Social determinants of health. https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1 (accessed 17.12.2020).

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

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

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

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

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

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

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

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

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

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

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[11] Cultural Competency (Note 9).

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

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

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

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

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

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

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

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

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

The normative question of access to healthcare for transgender and intersex individuals in Croatian law is in the focus of Ana Pošćić's and Adrijana Martinović's paper »Gender identity and access to healthcare in Croatia – legal framework«. In their contribution, the authors analyze guarantees and standards concerning the access of transgender and intersex persons to healthcare in Croatia. Beginning with an overview of the general legal framework for protection against discrimination of transgender and intersex persons in Croatia, Pošćić and Martinović then identify and analyse the main legal instruments applicable to this minority. In doing so, they take under consideration a legal framework aimed at collecting the necessary medical documentation for the change of legal gender, and the conditions under which access and financing of specific health services is possible. The authors conclude that although Croatian anti-discrimination legislation explicitly recognizes grounds of gender identity and gender expression, transgender persons in Croatia are better protected than intersex persons when it comes to access to health services and health protection. Furthermore, access to specific health services for transgender and intersex persons is hindered by lack of funding and non-transparent decision-making.

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

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

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

[16] Julian Bion, Elie Azoulay: The ethics of migration and critical illness. In: Intensive Care Medicine 42 (2016), pp. 256–257.

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

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

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

The following two contributions provide examples of healthcare for migrants in Slovenia and Germany. Nina Fritz's chapter »Healthcare of Migrants at the Reception Centre Brežice« examines the functioning of emergency medical care for migrants in Slovenia during the migration wave of 2015. Through analysis of documents from this centre, Fritz investigates the scope of medical assistance for migrants. The author concludes that the healthcare system in Slovenia was not prepared for the provision of adequate healthcare for migrants and refugees. The crisis could only be handled through the involvement of both healthcare providers and volunteers making the arrangements for receiving and treating migrants. When considering healthcare for migrants, it is important to look at healthcare in a broader context, particularly in light of their journey and the circumstances that led them to leave their home country. Necessary is also to account for the possible differences in individual medical conditions, religious beliefs of migrants and refugees, and the language barrier impeding communication in the doctor-patient relationship.

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

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

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

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

tion. They may lead to a lack of attention to their healthcare needs, worse health outcomes, and progressing social marginalization.[20]

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

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

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

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

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

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

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

I. Minorities

Alenka Janko Spreizer

Social exclusion of Roma from healthcare as a public space: another dimension of antigypsyism?

Abstract

Background: As the biggest European minority Roma are seen as disproportionately poor in many countries. According to the World Health Organisation and its Regional Office for Europe, evidence suggests that Roma are concentrated among the most underprivileged inhabitants. In 2011, the European Commission addressed health as one of the four areas within the European Union (EU) Framework for National Roma Integration Strategies up to 2020. Even though the regulation grants special status to the members of the Roma population in Slovenia, Roma are still regularly facing barriers in accessing adequate health care, living conditions, education and employment, which indicates social exclusion and violations of the fundamental human rights.

Methods: The text will be based on the anthropological study covering the study of literature. Qualitative research methods will be used in the analytical description of accessibility to public health institutions. In addition to the anthropological ethnographic method of fieldwork, we will use interviews with actors involved in public health, such as doctors and other medical staff and Roma.

Results: The results of ethnographic field research in Slovenia will contribute to illuminating obstacles in the field of everyday life and access to the public health system, which is one of the areas covered by the project called Barriers to a decent life of members of Roma settlements in the areas defined in the EU Framework for National Roma Integration Strategies up to 2020.

Discussion: Based on a critical review of the literature, the fieldwork and ethnographic study, the recommendation for the health policies and strategies will be drafted.

1. Introduction

After the collapse of the former state, the Socialist Federative Republic of Yugoslavia, and in the processes of reaching the »independent« state, the Roma, who live in structural disadvantages, and their situation in Slovenia came on the political agenda. During the accession process to the European Union, Roma in Slovenia were legally defined as an ethnic community with particular minority status. The situation of Roma, perceived as ethnic and culturally different, became »the challenge for the minority law«.[1] In these times of »transitions« from socialism to capitalism, the values of the society changed and several systems, such as the health system, educational systems, market, and the system of social welfare were transformed. These transformations processes were addressed in political everyday discourse as »transition« to democracy and the introduction of the neoliberal capitalist market. The public health system was also the target of the transformation with privatisation, gaining public concessions of privatized health institutions, bureaucratization, a changed system of social and health insurance, with social exclusion of some inhabitants of the new Slovenian state.

In comparison with the majority of Europeans, Roma as the biggest European minority are seen as disproportionately poor and socially excluded in many countries. According to the World Health Organisation and its Regional Office for Europe, evidence suggests that Roma are concentrated among the most underprivileged inhabitants. In 2011, the European Commission addressed health as one of the four areas within the EU Framework for National Roma Integration Strategies up to 2020.

1.1 Social constitution of the Roma

There exist many definitions, who are the Roma. In the primordial representations, Roma (in Slovenia and post-socialist Europe) are strongly connected with the foreign origin, Indian language, and in-

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[1] Vera Klopčič, Miroslav Polzer (Eds.): Poti za izboljšanje položaja Romov v srednji in vzhodni Evropi: Izziv za manjšinsko pravo [Paths for the improvement of the situation of the Roma in central and eastern Europe: The challenge for minority law]. Ljubljana 1999.

scribed nomadism, which was less understood as economic activity. Roma nomadism was often essentialized and represented as an »ethnic« trait which was implied as a major obstacle to education, employment, permanent housing, and health.[2] With these three »ethnic« traits these theories imply the reasons for a difficult relationship with the domestic population and their emplacement in local, national, and transnational space, and in EU institutions. Accordingly to critical scholars, it is better to understand the inscribed nomadism as the stereotype of eternal nomads who do not belong anyplace in Europe.[3]

Focusing on structural inequalities, human and minority protection rights, in the two last decades, the situation of Roma was put in the wider framework of Romani mobility and the question of the transformation of Europe, European-ness, and European citizenship.[4] Defining Roma as marginalized people who live in precarity due to structural inequalities in European societies in the globalized neoliberal economic market, especially in the time of conflicts or »the financial crisis«, scholars have been exploring the questions of Roma racialization and subjugation within the frame of European and migration studies.[5]

Within political discourse in several documents of international government organizations and human rights reports, as well as in transnational activism and media representations, at the beginning of the new millennium, Roma are widely defined as »a truly Eur-

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[2] Alenka Janko Spreizer: From a Tent to a House, from Nomads to Settlers. In: Nataša Gregorič Bon, Jaka Repič (Eds.): Moving Places: Relations, Return and Belonging. New York, Oxford 2016, pp. 172–193.

[3] Ismael Córtez Goméz, Marcus End: Introduction: Contemporary Dimensions of Antigypsyism in Europe. In: Ismael Cortés Gómez, Marcus End (Eds.): Dimension of Antigypsyism in Europe. Brussels 2019, pp. 19–27.

[4] Huub Van Baar: The European Roma: minority representation, memory, and the limits of transnational governmentality. Amsterdam 2011; Tina Magazzini, Stefano Piemontese (Eds.): Constructing Roma Migrants: European Narratives and Local Governance. Cham 2019.

[5] Stefano Piemontese, Tina Magazzini: Roma Westward Migration in Europe. Rethinking Political, Social, and Methodological Challenges. In: Magazzini, Piemontese: Construction Roma Migrants (Note 4), pp. 1–14; Annabel Tremlett, Aidan McGarry: Challenges Facing Researchers on Roma: Minorities in contemporary Europe: Notes towards a Research Program. ECMI Working Paper No. 62, European Centre for Minority Issues. 2013. https://www.files.ethz.ch/isn/159479/Working_Paper_62_Final.pdf (accessed 25. 9. 2020).

opean people«.[6] Within the Council of Europe, Roma are recognized as »a true European minority«.[7] »Europeanization of Roma minority representations« may be seen as a new phase in Europe's history and questions who the Roma would be.[8] The next sections will show, how these various representations of Roma are framed on the issue of the health or the Roma, which are reflected in the publication of Romani health and the discourse of my interlocutors.

1.2 Roma in Slovenia and their ethnic community status

Before Slovenia became independent in 1991 and during the pre-accession processes before joining the EU, the Roma in Slovenia became defined as »an ethnic community«. In the Constitution and according to Article 65, the situation and special rights of Roma »who live in Slovenia« are regulated by law. The minority rights of Roma are regulated by several acts, such as the Roma Community Act (ZRomS-1) of 2007 and 17 different laws within sectoral legislation under the competence of different ministries.[9] The Roma minority protective legislation is »harmonized« with the EU international law. In national legislation, the distinction between »autochthonous« and »non-autochthonous« Roma was initiated, giving the political rights for minority representation to those Roma who »historically« lived in Slovenia, mostly in the south-eastern and north-eastern regions of Slovenia, such as Dolenjska, Bela Krajina, Posavje, and Prekmurje, and excluding of the non-autochthonous Roma who were defined as migrants, having arrived in Slovenia in the time of former socialist Yugoslavia and living in urbanized settlements in Ljubljana, Maribor, and Velenje.

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[6] Will Guy: Romani Identity and post-Communist policy. In: Will Guy (Ed.): Between past and future. The Roma of Central and Eastern Europe. Hatfield 2001, pp. 3–32, here p. 16.

[7] Michaël Guet: Activities of the Council of Europe concerning Roma. In: Vera Klopčič, Miroslav Polzer (Eds.): Europa, Slovenija in Romi [Europe, Slovenia and Roma]. Ljubljana 2003, pp. 35–39, here p. 35; Van Baar: The European Roma (Note 4), p. 16.

[8] Van Baar: The European Roma (Note 4), p. 16.

[9] Alenka Janko Spreizer: Roma, Marginalization, Globalization and Conflicts Over Water: The Case of Slovenia. In: Borna Fuerst-Bjeliš, Walter Leimgruber (Eds.): Globalization, Marginalization and Conflict. Political, economic and social processes. Cham 2020, pp. 165–182.

This division between autochthonous and non-autochthonous was in future years a target for persistent criticism from institutions such as European Commission against Racism and Intolerance (ECRI) and the United Nations (UN). In the pre-accession period to the EU, in 1995, the government of the Republic of Slovenia adopted the Programme of Aid for the Roma Community that covered the areas of a local authority and the political representation of Roma, health, education, and social measures, security, employment, and housing. In later years, specific legal, social, and educational efforts for improving the situation of Roma were included in some programmes, such as the National programme of measures for Roma of the government of the Republic of Slovenia (NPUR 2010-2015;[10] NPUR 2017-2021[11]).

On the national level, the health of Roma was addressed at the very beginning in the Programme of Aid for the Roma Community in 1995, promising among others activities the preventive actions for improvement of the Romani health, national and university research, conferences, and register of Roma illnesses. The implementation of the measures and activities on healthcare were slowly realized in the following years and relatively late if we compare the public health system with the systems of education, social welfare, and employment. The research on the topics of the health and the Roma came on the agenda on the national level with the first national conference »Roma and health« in 2010,[12] with several local or regional projects, and with the national research project 2019. Readers of those publications may notice that the knowledge from socio-cultural anthropology of the cross-cultural approach was not well integrated and recognized as relevant for the health and the Roma. Following anthropological conceptualizations, health has a very different meaning for several ethnic and social groups as well as professional groups

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[10] Vlada Republike Slovenije: Nacionalni program ukrepov za Rome vlade Republike Slovenije. [National programme of measures for Roma of the government of the Republic of Slovenia] (NPUR) 2010–2015. https://www.gov.si/assets/vladne-sluzbe/UN/Dokumenti-Romi/65d892da3a/NPUR_2017_2021.pdf (accessed 30. 9. 2020).

[11] Vlada Republike Slovenije: Nacionalni program ukrepov za Rome vlade Republike Slovenije. [National programme of measures for Roma of the government of the Republic of Slovenia] (NPUR) 2017–2021. https://www.gov.si/assets/vladne-sluzbe/UN/Dokumenti-Romi/35778fa671/Program_ukrepov.pdf (accessed 30. 9. 2020).

[12] Ministrstvo za zdravje: Romi in zdravje: Zbornik prispevkov nacionalnih konferenc [Roma and health: Proceedings of national conferences]. Ljubljana 2020.

and there is not a common understanding of what being healthy or to have good health means.[13]

Even though the regulation grants special status as an ethnic community to the members of the Roma population in Slovenia, Roma are still regularly facing barriers in accessing health care, adequate living conditions, education, and employment, which indicates not only social exclusion and violations of the fundamental human rights but also high risk for the health. Despite recognition that Romani communities in Slovenia are heterogenic and diverse in terms of social status and culture, the conditions in which the majority of Roma live have serious consequences for their health. Additionally, social exclusion is manifested also in several obstacles when Roma approaching the public healthcare system, as it will be shown in the next sections.

2. Methods

This anthropological research on healthcare and Roma is a part of a wider interdisciplinary project of law scholars and anthropologists entitled »Barriers for a decent life of members of Roma settlements in the areas defined in the EU Framework for National Roma Integration Strategies up to 2020«. The project is partially focused on health and is intertwined with the rights to housing, water and sanitation, education, and social welfare/employment. For this contribution, first, it is important to show, from the anthropological point of view, with the method of critical analysis of discourse and interpretation of how the Roma in Slovenia as a particular excluded ethnic minority, that needs to be »socially integrated« due to their »social exclusion«, is labelled, and understood by health workers. Second, my intention is also to show that health and access to preventive healthcare for some groups of marginalized Roma in Slovenia is still limited. I aim to explain, how the lack of anthropological knowledge and awareness on the ethnic, cultural, and social diversity within specialist knowledge of healthcare workers and also wider Slovene society is reflected

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[13] Uršula Lipovec Čebron (Ed.): Kulturne kompetence in zdravstvena oskrba. Priročnik za razvijanje kulturnih kompetenc zdravstvenih delavcev [Cultural competencies and health care. Handbook for developing cultural competencies for healthcare workers]. Ljubljana 2016.

in the case of the relationship between the Roma and the healthcare workers.

For health research, the method of work with text and critical anthropological reading will be used. Based on the programmes NPUR[14] and publications on the Roma (public) health[15] special attention will be paid on the question, how the »social diversity« or »cultural diversity« approaches to health practice and education of Roma were approached and included in experts' papers on the Roma and healthcare.

Within our project, qualitative research methods, such as the ethnographic method of fieldwork, participant observation, and formal semi-structured interviews were used for the collection of the data. The research included interviews with Roma and healthcare workers, and also other interlocutors from 4 different municipalities from Dolenjska and Posavje area and 1 municipality in the Prekmurje region. In this text, I coded the localities, as L1 – L5, due to the preferred anonymity of my interlocutors. Localities were selected based on the fact, that some Roma families in those municipalities have difficult access to safe drinkable water and live in harsh living conditions, that present a high risk for the health. Additionally, those localities were selected because in previous years it was noticed, that at those locations the access to water and sanitation is limited and that the municipalities were facing resistance from the part of the majority population and sometimes the Roma and/or did not constructively approach to fulfilment the obligations written in the Slovene national programs of the Roma.

We entered the field through Romani assistants/facilitators, who are meant as bridges between Roma, education, and health system or local community, municipality public servants, or people who work with Roma, such as teachers, employees of Romani multi-purpose centres, or educationalists of the Roma community centres. In certain cases, we addressed the inhabitants of Roma camps (tabors) and settlements after we got the agreement from the non-formal local representatives of Roma. With a technic of preferred referencing or snowball we had chosen the experts from the health care public systems.

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[14] Vlada Republike Slovenije: Nacionalni program ukrepov 2010–2015 (Note 0); Vlada Republike Slovenije Nacionalni program ukrepov 2017–2021 (Note 1).

[15] Ministrstvo za zdravje: Romi in zdravje (Note 2); Tatjana Krajnc Nikolić (Ed.): Public health approaches for the Roma ethnic community in Slovenia. Ljubljana 2018.

We sent via e-mail formal invitations for interviews to Community Health Centres and emergency medical treatment in selected localities. We asked for cooperation experts from general practitioners and family healthcare practitioners, gynaecologists, psychiatrists, dentists, and paediatricians. Besides this, we have addressed also other medical staff, such as patronage nurses, midwives, and registered nurses. There was a big challenge to get the response and agreement for the interviews with medical stuff under the circumstances of »the new normality« in times of the pandemic of COVID-19 and new corona disease: Additional challenge was to gain the agreement for the recording of the interviews, on the side of Roma and medical staff. Besides this, we contacted experts in person or on the phone and try to organize a meeting for the interviews. All those interviews were transcribed and analysed.

Our questions for the Roma were about the accessibility to the health care system, healthcare insurance, and how often do they attend the community health care centres or healthy stations. We asked if they have selected doctors of family medicine, paediatrician, and gynaecologists. Then we queried how they understand the illness and when do they attend the community centres and how often are their visits. We interrogated about their relationships with doctors and other medical staff, how physicians are accessible if medical doctors come to the camp/settlement, and whether the communication and instructions are understandable. Due to pandemic measures of COVID-19, we could not observe Roma visits at the community health centre, but we were present in some workshops on health. Similar questions were posed also to the medical doctors and nurses, focusing also on their experiences at work with Roma, if they have any education about Romani culture and understanding Roma health, their conceptualizations of the body, gender, and taboos about gender. We asked about self-perception on their need for education on interculturality and cultural competencies.

3. Results

For anthropologists, the health system is one of the socio-cultural systems that is culturally constructed as it is the Roma health, body, and illness. Generally, the ethnocentric approach to understanding the Roma and their culture is noticed in the discourse of publications.[16] Additionally, some explanations of Roma and understanding of health are based on racialized eugenically inspired knowledge about genetically conditioned features,[17] which was reflected in the first Slovene monograph on the health culture of the Roma.[18]

3.1 Conceptualization of Roma and their health

Anthropologists had shown, how eugenics was connected with the intellectual legacy of a Slovene anthropologist Božo Škerlj, who had studied in the 1930s in Germany when national socialism was already spreading its harmful ideology and influence. It is known that Škerlj in the final years of his career was more reserved about some concepts of eugenics.[19] He was a leader of the first research on the Roma in Prekmurje, and after his death, Marij Avčin undertook the leadership, and the research team was less reflected in the usage of eugenic concepts. In the following years, the harmful eugenic conceptualizations were uncritically overtaken as fact up to nowadays and are reproduced amongst experts.[20]

In the health system and within social policies, Roma were mainly understood as one of the »socially vulnerable groups«, and formally, their costs for medical insurance are covered through social transfers.[21] National conferences on Roma and Health among other things stressed the »particularities of Roma culture and tradition« and awareness that the health is strongly connected with the living

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[16] Ministrstvo za zdravje: Romi in zdravje (Note 2).

[17] Janko Kersnik: Družinska medicina na stičišču kultur. 21. učne delavnice za zdravnike družinske medicine [Family medicine at the crossroads of cultures. 21. training workshops for family physicians]. Ljubljana 2004, here pp. 5–6.

[18] Jože Zadravec: Zdravstvena kultura Romov v Prekmurju [Health culture of Roma in Prekmurje]. Pomurska založba, Murska Sobota 1989.

[19] Duška Knežević Hočevar: Božo Škerlj – Slovene Anthropologist: Dilemmas and Controversies of an Early Professional Career. In: Anthropological Notebooks 4 (1996), pp. 25–34.

[20] Alenka Janko Spreizer: Vedel sem, da sem Cigan – rodil sem se kot Rom. Znanstveni rasizem v raziskovanju Romov [I knew I was a Gypsy – I was born a Rom. Scientific racism in Romani studies]. Ljubljana 2002.

[21] Boris Kramberger: Zdravstveno zavarovanje in dostop do zdravstvenega varstva populacije Romov v Sloveniji. [Health insurance and access to health care for the Roma population in Slovenia]. In: Ministrstvo za zdravje: Romi in zdravje (Note 2), pp. 41–43.

conditions, hygienic circumstances, and social security. Roma were recognised as »users of public health within the public health system«, implying that as poor inhabitants they could not afford to pay for private health services.

Picture 1 and 2: Huts, caravans and containers in the precarious Romani settlement at the margin of the woods and near industrial zone (Alenka Janko Spreizer, 28. 07. 2020). ■((very bad resolution! send better data, pls.))■

When talking to Roma at selected locations that were included in the ethnographic research, my first observations were that they live in terribly poor living conditions. As a group, the Roma of Slovenia deals with structural disadvantaged social position. Ghettoized settlements or camps, one of them legalized or on a path to legalization, and others very far from the conditions of »legality«, are located next to cemeteries, or next to newly created industrial zones, or along railroads on the outskirts of a village, at the fringe or in the middle of a forest, or on agricultural land. Life in such precarious conditions often without running potable water, electricity, and sewage infrastructure does not only lead to daily humiliation or dehumanization of people, it also presents a high risk for health. Nor in the socialist times, and neither in the transition period did the state or local communities in these selected cases established an adequate living environment for Roma that would not pose a high risk to their health, viewed through the generally prevailing health criteria in today's mainstream society.

My interlocutors have often shared generalized widely shared opinion, that Roma are blamed by themselves, because of their nomadic lifestyle as if this would be a reason for their plights in their localities. »They are definitely nomads; they go to their relatives 4 days after the baby was born. They are constantly moving around and due to their movement; it is not knowing who came as a newcomer to the

Romani camps«.[22] Beside these stereotypes on »natural« nomadism, which urges Roma to »constant movements«, the other stereotypes were the irresponsible parenting, idleness and the need for more severe surveillance and sanctioning of Roma.

Amongst my speakers, some of them seemed very emphatic and tried to explain themselves the reason for cultural misunderstandings with the Roma. According to one interlocutor:

> »Roma experience high stress, because they often find themselves in contradiction with that, that is primary, i.e. their culture and what is secondary, inclusion in a certain environment. This stress seems even more problematic when two different worlds meet, which needs to find some way of co-existence. Some Roma are better in this issue, and some others are less successful.«[23]

3.2 *Accessibility of the health system and attendance to community health care centres*

My interlocutors from health community centres expressed their opinion, that all Roma have medical insurance and that the health system is available to them on an equal basis as the other Slovene citizens. Some general practitioners claim, that there is a shortage of available personal health practitioners and that Roma would in these circumstances hardly choose one.[24] The general assessment from the part of the Roma interlocutors was, that medical preventive and curative services are accessible. However, even in the case that Roma have chosen personal health practitioner, generally, they do not attend doctors on a regular basis for preventive health care, and that they do not respond to invitations to national prevention programmes, such as the Svit programme (the national screening and early detection programme for colorectal cancer), the Breast cancer screening programme, called Dora and, Zora, a preventive programme for the detection of precancerous and early cancerous changes in the cervix. While one of my Romni interlocutors has been attending the health workshop, which was organised in a Roma settlement by the Educational Health Centre, she discovered that her blood pressure and the

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[22] Interview L4 with a patronage nurse. 7.9.2020

[23] Interview L5 with a medical practitioner and researcher. 9.9.2020.

[24] Interview L3 with a medical doctor. 7.9.2020.

blood sugar are high. She told me, that she has sometimes severe problems with breathing and chest pain, but she does not attend health care centres yet, despite she has problems and even though she has her own chosen general practitioner:

> »When someone is sick, a person goes to the doctor, you need to go there. You need to have one [of the doctors], who is selected and you go then. If you do not have one, you may go to emergency/urgency. Social insurance is paid and you may go to dentists and doctors. But I do not go regularly. We do not go for checking; we go only when we have pain. Pregnant women, those, who are young, are the only one, who go to doctors.«[25]

Before the COVID-19, it was possible to visit the community health centre without previous appointed meeting and some people would go and wait until the end of the day that they would be accepted.

Another Romni told me that she was worried that she would become ill. Her worries were connected with thoughts that she might not be having medical insurance. She admitted that she forgot to attend the Employment Agency for a meeting with her consultant and consequently, she was erased from the basis of the agency. Therefore, she lost the right to social support. She was very stressed because with the status of employment seeker, the right for social welfare was connected and the medical assurance was paid by responsible ministries. Medical staff in community health centres could not explain to me, whether in similar cases, when somebody had not lost the social support for 6 months, the person was being insured through the social transfers, and if the someone can attend the chosen medical doctors for preventive healthcare in this situation. Romani interlocutors told me, that in such cases they will go to an emergency room.

However, for medical staff, the presence of Roma in the community healthcare centre is disturbing, because, as someone said, »they walk around the building and create disorder, they go through the entrance for healthy people, they pass by the shortest way, they go through other ordinations not respecting the established rules«.[26]

In some of the localities, according to medical staff, the majority of children is vaccinated on systematic health checks when they start primary school. In one local community nurses recently started the field visits, and in summer in 2020 for the first time, she went to the

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[25] Interview L2 with a Romni. 30.7.2020.

[26] Interview L2 with a nurse. 30.7.2020.

localities where Roma live in camps, aiming to start with workshops on health in Romani camps. She was very enthusiastic but at the same time very lost, because the community health centre did not know the health situation of the Romani families in their municipality. In these localities, the patronage nurses are present after babies are born or they visit patients following the prescription of the doctors when they need to visit patients.

Educationalists who work on the education project »Together for knowledge«, told me, that they provide support to parents, when children, who are included in primary school do not have social assurance but need to visit the orthodontist. They help parents to provide social insurance cards for their children and explain to them, that they need to provide a referral for attending the specialist. Romani parents often do not know the bureaucratic procedure of the healthcare system, and an educationalist often explains to individual parents how the system works. They also explain that as a parent, they are under the law responsible for taking a child to medical examinations.[27] Several public servants from municipalities explained that they use the strategy »the carrot and the stick«, implying that they arrange certain things for Roma but only in a case if Roma would follow the obligations.

3.3 Visits of emergency medical care

The general opinion of my interlocutors from both sides of Roma and non-Roma is that Roma generally would use emergency medical care in case of the need to pay a visit to doctors. This practice of attending the community centres was explained with different connotations from the part of interlocutors. Municipality servants described that Roma go to the emergency medical treatment as »a herd«, implying uncivilized behaviours, such as »embarrassment because they don't want to wait in line, then get angry and finally people let them go on«, some of them are »verbally aggressive«. The social worker constructed the Roma as »panicking people« if they only have a headache, they immediately go to emergency health care:

> »They are very worried if they have problems with their health. Then they would start the process of the medical treatment, and then when they feel better they stop attending the doctors, they do not finish the

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[27] Interview L1 with an educationalist. 16.7.2020.

> treatment and maintain their health. When they go to doctors, they need support, and for this reason, there are many people at the EMC. If the youngest get ill, the whole family goes there. They are under big pressure and they are frightened.«[28]

The Romani assistant explained why at the emergency medical care conflicts may burst:

> »By our nature, we are panicking. We are worried about our relatives. As first, we are very many, it is our habit, that in the case of an accident of our relatives, we gather around the person. And at the emergency medical care this disturbed them. For this reason, we have the majority of conflicts.«[29]

The medical nurse explained her perception of the problem. According to her, they disturb the others and people let them go in front of the queue for the sake of peace. Besides their arrival in the crowd, she explained that some parents did not know how to respond to the high body temperature of the babies. The problem was that they did not know how to use the heat measure devices /thermometers or they did not have any. »They do not follow the routine of following the body temperature. It was difficult to work with them because there were four people who wanted to communicate with medical staff at the same time«.[30] Romani patients did not know how to explain the symptoms and they did not follow the routines which were learned and practiced through the regular attendance of medical care. Other users of medical treatment would follow those routines or protocols. »Working with Roma is very time-consuming because they did not understand or did not want to follow the procedures and rules. Sometimes Roma do not understand the language, and they do not know the protocol of communication when they go to doctors«.[31] To prevent cultural conflicts in the future, she works with the Romani multi-purpose centre in the locality. Although this interlocutor shows an emphatic approach to Roma, surprisingly, as several other medical staff, she never asked her patients, what being a healthy person means to Roma.

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[28] Interview L1 with social worker. 14. 7. 2020.

[29] Interview L3 with Romani assistant. 7. 9. 2020.

[30] Interview L2 with a nurse. 30. 7. 2020.

[31] Interview L2 with a nurse. 30. 7. 2020.

3.4 *Romani women, fertility and sexuality*

In national strategies and national programmes for Roma, the big importance is given to preventive healthcare of women and children. At the same time, the reproductive health of Roma is a point where the cultural construction of »Roma as the Others« is expressed. Healthcare for newborn babies by home care nurses was mentioned first and it was overstated in my interviews. Some of my interlocutors who were municipality servants were persuaded, that those nurses who attend Romani camps are endangered, due to some conflict events in the past. Consequently, those nurses visit Roma settlement in pairs and are vigilant to »aggression«, »improper behaviour«,[32] and sometimes violent attacks due to some past conflicts with individuals. For some of them, those safety issues were the argument why they find it difficult to work with Roma and that they do not like to work with them.

The majority of my interlocutors share the opinion, that in certain Romani environments in Slovenia, families are very patriarchal and that the women are oppressed. Many nurses hold the opinions, that having many children and being constantly pregnant almost automatically implies a kind of abuse from the part of the Romani men. Some nurses expressed that women are urged to please their men and that they discussed sexuality with them when they talk about health. One of those practitioners wanted to empower women by informing them, that they should negotiate with their partners about agreed sexual intercourse from both sides.

> »On the workshop with young Romani mothers, one of the girls said, that she would wish, that she could say, I want to have sexual intercourse when I wanted. I often give the impact on reciprocity, that women should have sex when they want to have it, and that they are not submitted to their man will, need.«[33]

However, this nurse claimed that talking about sex with Roma is connected with the education given in the schools and the workshop. Because abusive talk from the part of Roma minors is openly said to nurses these topics might be not taboo, was her understanding.

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[32] Interview L4 with a municipality servant. 21.7.2020.

[33] Interview L2 with a nurse. 30.7.2020.

Some other nurses also expressed empathy for young Roma women, but at the same time they labelled Romani women's bodies as »machines for giving the births«, and mothers »who do not do breastfeeding«.[34] In their urge to »help« those women they consult about contraception and found rejection form the part of their patients.

Because several interlocutors represented the »fact«, that »Romani women would practice early sexual intercourse after they give birth at the hospital, and for this reason, they need to leave the hospital immediately after the delivery«.[35] I discussed this bizarre and harmful stereotype with my anthropological experts who deal with intercultural competences and multilingual health dealing with communication within the intercultural contacts in the Slovene health system because this stereotypical representation of Roma as »the Other« was never before heard from my side. During the interview, it was said that this is quite wide guessing among medical staff. The stereotypic opinion is shared among many of the medical staff and is reproduced as a part of Romani culture.

When I asked a Rom, who is trained as a Romani facilitator, these opinions were denied and described as the lack of knowledge of the Romani culture.

4. Discussion

Due to the limited extent of this text, I discuss selected topics, which are in my opinion most important to address the Roma and intercultural healthcare. What is obvious from the reading of the publication on Roma and health, is a lack of knowledge from the contemporary Romani studies and anthropological or sociological understanding of the »Roma culture«. Roma culture is understood on a primordial base stressing the different or specific culture, Indian language as Sanskrit, Indian origin implying ethnicity or in at worst, the race. The understanding of the culture from the part of my interlocutors was not connected with the fact, that Roma lives in social disadvantages in different European societies for centuries. Social scholars, such as historians, sociologists, and anthropologists, among others, have shown that from the beginning of the transformation of the feudal system to

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[34] Interview L4 with a patronage nurse. 7.9.2020.

[35] Interview L4 with a nurse. 7.9.2020.

the capitalist system in several European countries, Roma were left behind and excluded,[36] due to their mobile economic activities, racialized physical appearance, estranged behaviour etc.[37] In certain European countries, they were enslaved for centuries.[38] The Roma were also left aside during the socialism, and were excluded in eastern European countries as citizens, despite the provided non-formal work in socialist economies, working as seasonal workers on the states' of private farms.[39] They also provide work in factories and provide services which were in comparison with others, less paid. In this vein, Romani nomadism must be understood as the economic activity of the Roma in Slovenia and was not inborn, as seen in the stereotype of eternal nomads who do not belong anyplace in Europe.[40] Romani nomadism was an economic response due to limited opportunities to survive in rural environments. My Roma interlocutor said that the nomadism was not careless vagrancy or joyful travel: it was hard work under precarious conditions of social inequality: as gatherers of mushrooms, snails, and herbs and as agricultural workers on farms they »work from March to November, from 6 a.m. until the dark«, and never knew if there would be enough goods and money to be able to sustain a family. Today's the »urge to move« of the Roma in certain localities, as perceived by nurses, is connected with the need of visiting their relatives in another quite distant location for the sake to make their laundry, because they do not have running water in their house and they do not go well along with the others inhabitants of the locality where they live.

Another point, which is important to raise is the persistent reproduction of eugenically inspired misconceptions of Roma and genetic transmissions of »the Roma behaviour«, that is often seen as criminalized, and aggressive. Instead of giving »the Roma behaviour« and »their culture« as genetically transmitted and connected with weak psychological abilities, which is eugenically inspired explanation, this contested behaviour should be understood as the personal response to social exclusion and Roma poverty, that needs to be understood as a consequence of structural violence. In these conditions of

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[36] Guy: Between past and future (Note 6).

[37] Cortés Gómez, End: Dimensions of Antigypsyism (Note 3).

[38] Achim Viorel: The Roma in Romanian History. Budapest 2013, pp. 27–85.

[39] Michael Stewart: The Time of the Gypsies. Boulder 1997.

[40] Córtez Goméz, End: Introduction (Note 3).

structural violence, Roma are exposed to social suffering.[41] This means that Roma live in the experience of distress and injustice, and those societal problems, that are connected with broader determinants of social exclusion under the conditions of the neoliberal economy, are often seen as personal problems, or in worst cases as »the Roma culture«.

The majority of my interlocutors connected the plight of Roma living in poverty, which is understood as structural violence, with psychological reasons for their deprivation: many Roma in Slovenia are also labelled as people with reduced psychological abilities, and those inscribed psychological features were seen as a genetically transmitted pattern that leads to increasing poverty. Last but not least, it is important to note that one of my interlocutors questioned if the psychological tests fit the purpose and if they are neutral. Or they may not be useful for people who do not belong to mainstream cultures. In a recent publication, it was shown that in forensic psychology in Slovenia psychological tests are questionable because they are inappropriate as outdated, non-standardized, and scientifically and ethically controversial.[42] With it, we can ask ourselves if perhaps the psychological tests for Roma are not flawed either.

It is important to underline, that Roma, despite their health insurance, still do not attend preventive health programmes. It was shown, that the reasons were multiple: my interlocutors understand that »they are healthy if they do not experience the pain«.[43] They feel that they are not taken seriously, in a case when they came to the emergency health unit. In most cases, they are taken as difficult patients, unable to communicate properly, according to medical protocols. From the response of medical staff, we may conclude, that they are ethnocentrically treated. Generally, it is seen, that the Roma should get an education on how to approach to the hospital. The majority of medical staff did not reflect, that they might need education on cultural competences. The problem is not only the barrier of the knowledge of the Slovene language: actually, it was never exposed that the health centres should have Romani interpreter or, that there

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[41] Barbara Rylko-Bauer, Paul Farmer: Structural violence, poverty, and social suffering. In: David Brady, Linda Burton (Eds.): The Oxford Handbook of the Social Science of Poverty. Oxford 2016, pp. 47–74.

[42] Igor Areh: Forensic assessment may be based on common sense assumptions rather than science. In: International Journal of Law and Psychiatry 71 (2020), pp. 1–10.

[43] Interview L2, with a Romni. 30. 7. 2020.

is a lack of the knowledge on Roma culture. The need to educate Roma about preventive health care was underlined, but at the same time, my non-Roma interlocutors were blind for intercultural approaches to health. The majority of them have never talked to Roma and question, how do they understand the body and the health. Instead, they offer ethnocentric explanations about female Romani bodies, and educate women for not being »a machine for reproduction«. Conversely, the majority of the interlocutors did not realize that sex education is tabooed and culturally constructed to decency and respect. When Roma were addressing medical staff with sexual abusive terms, they use sexuality as the strategy for the maintenance of ethnic boundaries.[44]

5. Conclusion

What is seen as problematic is the fact, that the medical workers rarely question their competences for describing »the Roma culture«. A careful listener may notice, that the words about culture are as a black box, where several stereotypes, sometimes implicitly and often explicitly, are packed, such as »Roma are aggressive«, »Roma do not follow the rules, »Romnis are not responsible mothers«, »they are not responsible to their health«, implying as if Roma would have chosen their way of socially excluded life in the severe conditions of structural disadvantage and poverty. Those representations were in many cases generalized to collectively Roma. »Perpetuating and affirming discriminatory stereotypes of and against Roma« is seen as one of the dimensions of antigypsyism. Some of my interlocutors in the chosen localities were blaming Roma for their »social, political, cultural, economic and public health problems«. For a conclusion, we invite readers to reflect the explanation of the phenomenon of antigypsyism:

> Antigypsyism/anti-Roma discrimination is a manifestation of individual expressions and acts as well as institutional policies and practices of marginalization, exclusion, physical violence, devaluation of Roma cultures and lifestyles, and hate speech directed at Roma as well as other individuals and groups perceived, stigmatized, or persecuted during the Nazi era, and still today, as »Gypsies«. This leads to the treatment of Roma as an alleged alien group and associates them with a series of pejorative stereotypes and

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[44] Judith Okely: The Traveller-Gypsies. Cambridge 1983.

distorted images that represent a specific form of racism (…). Antigypsyism/anti-Roma discrimination is a multi-faceted phenomenon that has widespread social and political acceptance. It is a critical obstacle to the inclusion of Roma in broader society, and it acts to prevent Roma from enjoying equal rights, opportunities, and gainful social-economic participation.[45]

To our understanding, avoiding antigypsyism, there exist an urgent need to bring intercultural education about Roma in healthcare.

Acknowledgements

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[45] International Holocaust Rememberance Alliance: Working definition of antigypsyism/anti-Roma discrimination 2020. https://www.holocaustremembrance.com/resources/working-definitions-charters/working-definition-antigypsyism-anti-roma-discrimination (accessed 20.10.2020).

Erika Zelko, Zala Peterka, Danica Rotar Pavlič

How challenging is the Slovenian healthcare system for the Roma population?

Abstract

Introduction: Health systems overall in the world are becoming increasingly complex, so functional health systems that provide high-quality services are among the priorities of governments. The Roma in Prekmurje, the far northeaster part of Slovenia, are a unique ethnic group and in many respects different from other Roma in Slovenia. Ten years after the first study, we asked Roma representatives to determine their attitudes towards the healthcare system and estimate how challenging the system is for them now.

Methods: We conducted 23 interviews with Roma representatives per phone. The participants were between 22 and 74 years of age, with the average age being 38.96 years old; 48 % were men and 52 % women. We used the process of qualitative content analysis: coding, triangulation, obtain and verify results.

Results: We determined five logical categories that explain the attitudes of the Roma towards health, satisfaction, problems and prospects and the functioning of the health system on the local level. These are: experiences with the healthcare system, personal healthcare, patient – physician relationship, barriers to access the healthcare system and cultural sensitivity.

Conclusion: In the last eight years, a lot has changed in the society. Roma are a part of this change and have also witnessed the adaption of the healthcare system during the epidemic times. Mostly they are very satisfied with the changes and manage the challenges in the healthcare system well, but their also recognize new barriers to face with, like low health literacy.

1. Introduction

Health systems overall in the world are becoming increasingly complex, so functional health systems that provide high-quality services are among the priorities of governments. They should also serve increasingly ethnically diverse populations in most countries.[1] This requires cultural sensitivity and competence of the health care providers on all levels of care.[2] Understanding that meeting the needs of minorities improves health systems for everyone is an important paradigm change for the general population and policy makers.[3] It is important to stress that vulnerable populations are seldom homogenous; they include subgroups with potentially various needs.[4] One of the largest minority groups in Europe are Roma with an estimated population of just over 11 million, which comprises approximately 1.35 % of Europe's total population.[5] This ethnic community lives in multiple homelands, has an abundant cultural heritage and distinct itself through a specific way of life. Predominantly the Roma live in Central and Eastern Europe (CEE) – their population in the CEE countries is estimated at about 5.2 million.[6] Despite progressing assimilation of the Roma with majority populations, large numbers of individuals from this minority group continue to live on the margins of society, often in segregated settlements and bad housing conditions, and in many cases they are excluded from similar opportunities in mainstream education and the labour market, compared to the rest of the population.[7]

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[1] Raj S. Bhopal: The quest for culturally sensitive health-care systems in Scotland: insights for a multi-ethnic Europe. In: Journal of Public Health 34 (2012), pp. 5–11.

[2] Martina Bofulin, Jerneja Farkaš Lainščak, Karmen Gosenca, Ajda Jelenc, Marjeta Keršič Svetel, Uršula Lipovec Čebron, Sara Pistotnik, Juš Škraban, Darja Zaviršek: Kulturne kompetence in zdravstvena oskrba: Priročnik za razvijanje kulturnih kompetenc zdravstvenih delavcev [Cultural Competences and Health Care: A handbook for developing the cultural competencies of health professionals]. Ljubljana 2016; John Lowe, Cynthia Archibald: Cultural diversity: the intention of nursing. In: Nursing Forum 44 (2009), pp. 11–18; Elizabeth Horevitz, Jennifer Lawson, Julian C. Chow: Examining cultural competence in health care: implications for social workers. In: Health and Social Work 38 (2013), pp. 135–145.

[3] Bhopal: The quest for culturally (Note 1); Erika Zelko, Igor Švab, Alem Maksuti, Zalika Klemenc-Ketiš: Attitudes of the Prekmurje Roma towards health and healthcare. In: Wiener klinische Wochenschrift 127 Suppl. 5 (2015), pp. 220–227.

[4] Andrew Booth, Louise Preston, Susan Baxter, Ruth Wong, Duncan Chambers, Janette Turner: Interventions to manage use of the emergency and urgent care system by people from vulnerable groups: a mapping review. Southampton 2019.

[5] Nikesh Parekh, Tamsin Rose: Health inequalities of the Roma in Europe: a literature review. In: Central European Journal of Public Health 19 (2011), pp. 139–142.

[6] Zelko, Švab, Maksuti, Klemenc-Ketiš: Attitudes of the Prekmurje Roma (Note 3).

[7] János Sándor, Zsigmond Kósa, Klára Boruzs, Julianna Boros, Ildikó Tokaji, Martin McKee, Róza Ádány: The decade of Roma Inclusion: did it make a difference to health

For this community, several types of barriers to health service use have been reported, and include factors such as health system organisation, discrimination, culture and language, health literacy, service-user attributes and economic barriers.[8]

The main results from 2012 are represented in the article published in Wiener Klinische Wochenschrift.[9] In this article we will focus on the data collected in 2020. The aim of our study was to analyse the relation of Prekmurje Roma to health and the Slovenian healthcare system ten years later. In this study, we take advantage of two unique surveys, undertaken using the same methodology, of Roma living in settlements of Northeast part of Slovenia, addressing the changes between 2010 and 2020 in accessing the health system. In 2010 the most important challenges, reported from Roma were: lack of information about preventive medicine in Roma population, the need for improvement of the communication between the Roma and healthcare staff, poverty and high unemployment, unkindness of the healthcare staff, neglect of Roma patients′ problem and lack of understanding Roma to foster trust between Roma and healthcare staff.

2. Methods

This was a qualitative study conducted among the Roma in Prekmurje, Slovenia. One of the researchers (E. Z.) conducted semi-structured interviews with 23 Roma (Table 1), who already participated at the first research in 2010. Two participants from the first study died in the meantime. Because of the epidemic of coronavirus, we conducted 23 interviews per phone. The participants were between 22 and 74 years of age (Table 1). We used purposeful sampling, typical for qualitative research, taking care to cover women and men, and both rural and town residents from different settlements.[10] All participants agreed to be interviewed. We used five questions from the

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and use of health care services? In: International Journal of Public Health 62 (2017), pp. 803–815.

[8] Alison McFadden, Lindsay Siebelt, Anna Gavine, Karl Atkin, Kerry Bell, Nicola Innes, Helen Jones, Cath Jackson, Haggi Haggi, Steve MacGillivray: Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. In: European Journal of Public Health 28 (2018), pp. 74–81.

[9] Zelko, Švab, Maksuti, Klemenc-Ketiš: Attitudes of the Prekmurje Roma (Note 3).

[10] Margrit Schreier: Qualitative content analysis in practice. Los Angeles 2012.

questionnaire, as was developed and used at the first study.[11] We asked the following general questions: (1) What do you think about the services offered by healthcare centres, especially family medicine? (2) What do you expect from healthcare (from society, self-care, healthcare in general)? (3) How could one improve the health of the Roma? (4) Do you or your relatives encounter any problems when you are seeking help from a physician? and (5) Have you ever experienced anything unpleasant in a healthcare centre because you are Roma?

Besides those pre-formulated questions, during the research implementation, we asked additional sub-questions, for example »Because you are Roma?« which are typical of semi-structured interviews.[12] All of the interviews were audio-recorded and transcribed verbatim by a trained administrator. For the systematic examination of the collected data, we used qualitative content analysis (QCA), a method derived from the communication sciences which is useful for systematic analysis in a wide range of scientific domains,[13] as well as in the field of the Romani people and their attitudes towards health and healthcare services.[14] We used inductive content analysis including coding, creating categories and abstraction to formulate a general description of the research topic.[15] Two researchers (E. Z. and D. R. P.) independently coded the interviews, and the third (Z. P.) researcher supervised the process. In the study, we used a data-driving coding scheme and formed 65 codes sorted in 5 logical categories/themes to detect patterns in the analysed data, and to explain the attitudes of the Roma from Prekmurje towards health and healthcare.[16] During the coding process, the two researchers sought consensus. When this failed, we tried to achieve intercoder agreement about differently per-

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[11] Zelko, Švab, Maksuti, Klemenc-Ketiš: Attitudes of the Prekmurje Roma (Note 3).

[12] Schreier: Qualitative content analysis (Note 0); Christel Hopf: Qualitative interviews: An Overview. In: Uwe Flick, Ernst von Kardorff, Ines Steinke (Eds.): A companion to qualitative research. London 2004, pp. 203–208.

[13] Schreier: Qualitative content analysis (Note 0); Satu Elo, Helvi Kyngäs: The qualitative content analysis process. In: Journal of Advanced Nursing 62 (2008), pp. 107–115.

[14] Danica Pavlić, Erika Zelko, Janko Kersnik, Verica Lolić: Health beliefs and practices among Slovenian Roma and their response to febrile illnesses: a qualitative study. In: Slovenian Journal of Public Health 50 (2011), pp. 169–174.

[15] Elo, Kyngäs: The qualitative content analysis (Note 3).

[16] Schreier: Qualitative content analysis (Note 0).

ceived parts of an analysed text to fit the created category (also known as the »unitising process«).[17]

3. Results

Participants		
	N = 23	%
Gender		
Male	11	48
Female	12	52
Marital status		
Married	17	73.9
Single	4	17.4
Divorced	1	4.3
Widowed	1	4.3
Educational status		
Without educational qualifications	4	17.4
Elementary school	13	56.5
Vocational school	3	13.0
High school	2	8.7
Faculty	1	4.3
Employment		
Employed	6	26.2
Student	1	4.3
Housewife	5	21.7
Retired	4	17.4
Unemployed	7	30.4
Housing		
Wooden house	1	4.3
Brick house	21	91.3

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[17] Schreier: Qualitative content analysis (Note 0); Elo, Kyngäs: The qualitative content analysis (Note 3).

Participants		
	N = 23	%
With relatives	1	4.3
Tap water	22	96
Electricity	23	100
Sewerage	17	73.9
Medical insurance	22	96

Table 1: Demographic characteristics of participants

We identified the following categories: experiences with the healthcare system, personal healthcare, patient -physician relationship, barriers to access the healthcare system and cultural sensitivity.

3.1 *Experiences with the healthcare system*

Most of the interviewees reported good experiences with the healthcare system and the services provided by the health centres. Mostly they are very satisfied with the new methods introduced in the last years at the practices. Electronically medication prescriptions and referral letters have shortened the waiting time at the practices. Their main complaints are related to long waiting times and limited time for medical examinations at the secondary health care level and the expensive non-compulsory healthcare insurance. They also miss the willingness of some healthcare providers for performing home visits at the settlements. Some examples are as follows:

> »It is better because of e-recipes and e-referrals. You just call, order, and then take over in pharmacy and referrals are already waiting at specialist. Yes, this is much better, you do not have to wait at the practice.«
>
> »They should understand it better and come on house visit when we need them. Not everyone in the village has a car.«
>
> »Legislation should regulate waiting times. I have been waiting for a year to get my veins cleaned. In Austria, this is better. They should hire more doctors and nurses.«
>
> »Insurance is expensive, the extra one, if you don't have it, you have to pay a lot of money extra. It would be better if there was only one.«

3.2 *Personal healthcare*

Most of them believe that everyone is responsible for their own health. They emphasised the importance of prevention, a healthy lifestyle and good communication and trust with the personal physician. They also highlighted the importance of making a timely visit to the physician, and the risk of treatment rejection. Also, the pandemic situation was an important topic for them. Here are some interesting examples:

> »Before corona, we went to preventive check-ups more often, only for addiction problems they should come in the village to say something.«
>
> »I was in the model practice, we had a nice talk, very simple and understandable.«
>
> »We were careful about the virus, we washed our hands, the boss gave us disinfectants, and our old people did not walk around.«
>
> »Maybe we should know even more about children's health … I have a child with autism.«

3.3 *Patient – physician relationship*

It should be noted that the answers and compliments given in the interviews refer to the interviewee's personal physician and health centres in the local community. In relation to the study conducted in 2010, they mostly agree, that the younger generation of physicians are better educated in Roma culture and cultural sensitivity.

> »You can come across mean people everywhere. We have good and bad Roma, we have good and bad doctors. Adding oil to a fire is not good. You must be diplomatic and solve everything diplomatically. We used to be more dependent on the doctor, but now you look it up on Google and you can help yourself.«
>
> »Young doctors are better; they do not differentiate between Roma and non-Roma.«
>
> »I respect doctors and nurses, and they respect me.«
>
> »Doctors can't do everything. And we have to tell them the truth so that they can help us.«

3.4 Barriers to access the healthcare system

The interviewees stressed the importance of good communication, education and increasing the health literacy in Roma community. They also express the worries about some prejudice related to the pandemic situation and Roma spreading the virus. Use of digital technology and computer is also an important barrier to access the physicians.

> »We should strengthen action to raise health literacy through the consistent implementation of the Community approach …«
>
> »I have a feeling they think we Roma have corona, but believe me, Roma will not transmit the virus.«
>
> »Now with corona, it is harder to get to the doctor.«
>
> »I don't understand the computer so well, so I don't use it.«
>
> »The problem is that doctors work for the insurance company and they do not look after the patient. Not everyone is like that, there are more problems with those who are not from here.«

3.5 Cultural sensitivity

Cultural awareness or sensitivity is the first step towards cultural competency.[18] Our interviewers pointed out, that some positive changes have happened in the last ten years, but they emphasized also the need of Roma mediators for higher quality of care provided at the health system and expose some still existing problems.

> »Provide information in as simple a language as possible, approach them in settlements for the sake of trust and better access, introduction of Roma mediators – Roma health workers.«
>
> »The staff is more open to the Roma community, they know more about the Roma community, our habits and customs.«
>
> »We have dental problems, especially children. 90 % of Roma are afraid of the dentist. This is a big problem for us.«

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[18] Naser Z. Alsharif, Lisa Brennan, Jeanine P. Abrons, Elias B. Chahine: An Introduction to Cultural Sensitivity and Global Pharmacy Engagement. In: American Journal of Pharmaceutical Educaction 83 (2019), pp. 592–603.

4. Discussion

We determined five logical categories that explain the attitudes of the Roma towards health, satisfaction, problems, prospects, and the functioning of the health system at the local level. These are: experiences with the healthcare system, personal healthcare, patient-physician relationship, barriers to access the healthcare system and cultural sensitivity. In comparison to 2010, the findings reveal several changes, for better and for worse. On the one hand, Roma agree that the healthcare staff is more open to their problems and especially the young physicians are also more culturally sensitive. They more often participate at the preventive programs and are very satisfied with the possibilities to order the medication and referral letters online. On the other hand, the employment situation has worsened, the surcharges for medicines have increased and the prejudice about infectious Roma in the pandemic time appeared. Another important conclusion of our study is that the Roma are willing and ready to participate in improving their health status. Most of them are aware that Roma culture is the important determinant of their health. Health disparities emerge and persist through complex mechanisms that include socioeconomic, environmental, and system-level factors.

The European Union (EU) is committed to reducing health inequalities between the general population and the Roma population. Since 2011, all member states have designed national strategies on Roma inclusion with targets for education, employment, housing, and health. The EU has also made improving access to healthcare a priority in order to promote social inclusion and equal opportunities for all.[19] Slovenia has a social health insurance system with a single public insurer, the Health Insurance Institute of Slovenia (HIIS), providing universal compulsory health insurance. Three private companies provide voluntary health insurance (VHI), which is mainly used by patients to cover co-payments. Co-payments apply to most types of health services and vary between 10 % and 90 %, depending on the

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[19] Communication from the Commission to the European Parliament, the Council, The European Economic and Social Committee and the Committee of the Regions: National Roma Integration Strategies: A First Step in the Implementation of the EU Framework, European Commission 2012. COM/2012/226 Final. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2012:0226:FIN:EN:PDF (accessed 21.9.2020).

type of service.[20] Regarding to our interviewers the co-payment is increasingly becoming a problem to them because there are still surcharges to pay for some medicine needed.

One of the most basic requirements of general practice is access, which is universal in Slovenia; in one study 95.3 % of patients reported no discriminating actions such disrespectful behaviour with regard to their ethnic background or gender, no negative or uncaring attitude by healthcare professionals, or situation in which they felt that other patients received better treatment.[21] Roma agreed that, they do not have problems regarding discrimination in the health care settings, but they exposed the new prejudice about infectious Roma that increased in pandemic times.

Cobbinah and Lewis remark that:

> Racism affects health at different levels: institutional racism is a structural and legalized system that results in differential access to health services; cultural racism refers to the negative racial stereotypes, often reinforced by media, that results in poorer psychological and physiological wellbeing of the minorities. Lastly, interpersonal racism refers to the persistence of racial prejudice that seriously undermines the doctor-patient relationship.[22]

For example La Parra-Casado et al. concluded that the discrimination of Spanish Roma relay mostly to the quality of care, among other on the factors such as experiences of discrimination in their contact with health professionals.[23] In another example, the barriers for access to healthcare for Roma-population in Ghent included factors such as financial constraints, the complexity of the health system and the role

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[20] OECD/European Observatory on Health Systems and Policies: Slovenia, Country Health Profile 2017. State of Health in the EU. https://ec.europa.eu/health/sites/health/files/state/docs/chp_sl_english.pdf (accessed 30. 11. 2020).

[21] Suzana Kert, Igor Švab, Maja Sever, Irena Makivić, Danica R. Pavlič: A cross-sectional study of socio-demographic factors associated with patient access to primary care in Slovenia. In: International Journal for Equity in Health 14 (2015), https://doi.org/10.1186/s12939-015-0166-y.

[22] Stefania S. Cobbinah, Jan Lewis: Racism and Health: A public health perspective on racial discrimination. In: Journal of Evaluation in Clinical Practice 24 (2018), pp. 995–998.

[23] Daniel La Parra-Casado, Paola A. Mosquera, Carmen Vives-Cases, Miguel San Sebastian: Socioeconomic Inequalities in the Use of Healthcare Services: Comparison between the Roma and General Populations in Spain. In: *International Journal of Environmental Research and Public Health 15* (2018), https://doi.org/10.3390/ijerph15010121.

of trust between patient and care provider in the care-giving process.[24] In our study the Roma also exposed the health literacy as a barrier to better quality of health care. To similar conclusion come the Hungarian researchers, they pointed out that »(…) interventions in Roma communities should focus not only on health literacy among Roma but also on the health care system and health care professionals.«[25] One of the prioritized topics of our interviewers were mental and child health. Similar conclusion also made researcher in USA.[26] Barriers in access to the health care faces not only Roma, but also other minority group. Romanelli and co-authors identified social-structural factors and individual factors like health literacy and stigma.[27] With progressing understanding of socioeconomic determinants of health over the past decade, visible becomes relationship between inequalities and health – societies with greater inequalities are less healthy overall.[28] Also because of that the importance of culturally sensitive and culturally competent healthcare is increasing.

Within this context, Betancourt et al. state that:

> »Cultural competence« in health care entails: understanding the importance of social and cultural influences on patients' health beliefs and behaviours; considering how these factors interact at multiple levels of the health care delivery system (e. g., at the level of structural processes of care or clinical decision-making); and, finally, devising interventions that take these issues

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[24] Lise G. M. Hanssens, Ignaas Devisch, Janique Lobbestael, Barbara Cottenie, Sara Willems: Accessible health care for Roma: a gypsy's tale a qualitative in-depth study of access to health care for Roma in Ghent. In: International Journal for Equity in Health 15 (2016), https://doi.org/10.1186/s12939-016-0327-7.

[25] Pavol Jarcuska, Daniela Bobakova, Jan Uhrin, Ladislav Bobak, Ingrid Babinska, Peter Kolarcik, Zuzana Veselska, Andrea Madarasova Geckova, HEPA-META team: Are barriers in accessing health services in the Roma population associated with worse health status among Roma? In: International Journal of Public Health 58 (2013), pp. 427–434.

[26] Susan Dorr Goold, C. Daniel Myers, Marion Danis, Julia Abelson, Steve Barnett, Karen Calhoun, Eric G. Campbel, Lynette LaHahnn, Adnan Hammad, René Pérez Rosenbaum, Hyungjin M. Kim, Cengiz Salman, Lisa Szymecko, Zachary E. Rowe: Members of Minority and Underserved Communities Set Priorities for Health Research. In: The Milbank Quarterly 96 (2018), pp. 675–705.

[27] Meghan Romanelli, Kimberly D. Hudson: Individual and systemic barriers to health care: Perspectives of lesbian, gay, bisexual, and transgender adults. In: American Journal of Orthopsychiatry 87 (2017), pp. 714–728.

[28] Parekh, Rose: Health inequalities of the Roma (Note 5).

into account to assure quality health care delivery to diverse patient populations.[29]

5. Conclusion

The Roma people are an authentic ethnic minority in Slovenia. Despite of years and years work in the Roma community they still face a lot of challenges in accessing the complex health care system. In comparison to 2010, the findings reveal several changes, for better and for worse. For example, they reported that more Roma made the preventive checks in the last years, they use more often new digital technologies to find some health information, they warmly welcomed the online prescriptions and referral letters at primary health care. But on the other hand, they recognize new barriers like low health literacy, increased mental problems at adults and dental problems at the children. They express the need for Roma mediators to help them to navigate through the complex healthcare system.

As a result of pandemic in 2020, Roma communities are also facing further changes and discriminations. Prejudice about contagious Roma have re-emerged. Anxiety and worries about the future, especially because they fear an increase in poverty due to unemployment has risen. Roma communities have made in the last years a lot of changes, but still there are some challenges for the coming years.

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[29] Joseph R. Betancourt, Alexander R. Green, J. Emilio Carrillo, Owusu Ananeh-Firempong: Defining cultural competence: a practical framework for addressing racial/ ethnic disparities in health and health care. In: Public Health Reports 118 (2003), pp. 293–302.

Blaž Kovač

Roma in Slovenia – a story of disaster

Abstract

Background: The Roma minority is one of the most marginalized communities within Europe. In Slovenia, the situation is similar, the most challenging being in illegal Roma settlements persisting from the times of ex-Yugoslavia and not addressed since.

Methods: An analysis, made upon the available information, combined with the cooperation of Roma communities in the field and legal proceedings of Amnesty International Slovenia from 2013–2020. The focus of the analysis is the law with a focus on human rights and considerations of healthcare issues.

Results: In 2020, the European Court of Human Rights delivered a negative decision in two Roma cases on the question of the right to water, the right to sanitation and other aspects of human rights. Strategic litigation was not successful, as well as a referral to the court's Grand Chamber. The Slovene political system with included minority protection is not effective at all. The healthcare system is aware of the situation of the poor health of Roma but is not proactive at all.

Conclusions: The results show that the Roma live parallel lives and that the Slovene state completely lacks the will to address this situation in some areas of Slovenia. The right to water with significant healthcare effects is a Slovene Constitutional right and is a recognized independent right under the UN system, but lacks implementation mechanisms. In practice, human rights do not reach the communities in the field.

1. Introduction

On 10 March 2020 the European Court of Human Rights (ECtHR) ruled to dismiss the complaints of two Roma families from Škocjan and Ribnica, who argued their human rights were violated by the

Republic of Slovenia.[1] A referral to the court's Grand Chamber, basically a complaint, was filed by our legal team in June 2020 and a decision to reopen the case was denied on 8 September 2020. The decision marks the end of a long strategic litigation effort, managed by Amnesty International Slovenia with the help of attorney Nina Zidar Klemenčič, to seek changes in the field through courts.

These two families were and still are living in illegal settlements – in illegal housing, one of the families relocated literally to the forest during the proceedings. They were and still are living without access to water, electricity, sanitation or other public services. The main point of the cases was linked to the European Convention on Human Rights provisions on private and family life, access to water, electricity, social state measures, health issues and prohibition of torture and other inhuman or degrading treatment, especially in municipal actions and the passiveness of social services. Complainants also claimed they were discriminated against.

The decision of ECtHR was a surprise to all involved in the process. It effectively stopped all efforts to change the situation in the field through legislative action. Even more, the decision locked Slovenia in the current state, usually described as despair. Now, players from the minority, official institutions and the civil society, simply cannot envisage any significant progress in any field.

I agreed to write this paper well before the ECtHR decision but after the decision was made I and Amnesty International professionally do not cover Roma issues anymore. This paper marks the end of our professional engagement on Roma minority issues.

2. General overview of Roma health and living conditions

Official records show that ten school years ago, 251 Roma pupils entered the 1st grade of Primary school.[2] In the last school year (2018/19), out of these 251 pupils, only 99 entered the 9th grade. The last

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[1] European Court of Human Rights: Judgment in the cases Hudorovič and Novak (24816/14, 25140/14). http://hudoc.echr.coe.int/eng?i=001-201646 (accessed 16.10.2020).

[2] Pedagoški inštitut: Nacionalna evalvacijska študija uspešnosti romskih učencev v osnovni šoli. Zaključno vsebinsko poročilo [National evaluation study of the performance of Roma students in primary school. Final content report]. Ljubljana 2011, p. 98.

information was included in the reply of the Ministry of education we received by email on 5 August 2019 in response to our questions on Roma success rates for the school year 2018/19. Similar conclusions can be found in the Report of the Commissioner for Human Rights[3] following his visit to Slovenia in 2017. There is no information on how many actually completed Primary school. A nation-wide 60 % dropout rate for Roma pupils is disastrous, keeping in mind these figures also include relatively less-challenging areas of larger cities and Prekmurje. In Dolenjska, the situation is thus even more worrying with Novo mesto Bršljin school officially claiming less than 1 % Primary school completion rate.[4] The state does not collect any disaggregated data on Roma education at all. Legally it is not compulsory to actually attend classes in Slovenia. It is enough to be just enrolled in the school. The school inspection monitors mechanisms to actually try to enforce attendance. Sometimes in the past Amnesty International challenged inspection decisions against Roma parents and succeeded. The information regarding special needs schooling are scarce, but comparing general population information with Institute of social work information show the level of Roma in special schools is 11.4 % of the Roma pupils, while for the majority this percentage is 6.55 %.[5] Unofficially, the National Education Institute agrees the problem lies partly in the Slovenian-language-only tests. The state does not collect any disaggregated data – all the information on this issue was gathered in the field yearly by Amnesty International Slovenia, Mladina newspaper and some Roma councilmembers.

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[3] Report by Nils Muižnieks, Commissioner for Human Rights of The Council of Europe following his visit to Slovenia from 20 to 23 March 2017 (11. 7. 2017), para 78. https://rm.coe.int/report-on-the-visit-to-slovenia-from-20-to-23-march-2017-by-nils-muizn/1680730405 (accesssed 19. 12. 2020).

[4] Amnesty International: Podatki o šolskem uspehu romskih otrok kažejo, da se jih pušča na cedilu [Data on the school success of Roma children show that they are being let down] (4. 10. 2018). https://www.amnesty.si/podatki-o-solskem-uspehu-romskih-otrok-kazejo-da-se-jih-pusca-na-cedilu.html (accessed 16. 10. 2020).

[5] Republic of Slovenia: Podatki v zvezi z učenci s posebnimi potrebami v osnovnih šolah s prilagojenim izvajanjem in dodatno strokovno pomočjo [Data on pupils with special needs in primary schools with adapted implementation and additional professional assistance]. http://www.mizs.gov.si/fileadmin/mizs.gov.si/pageuploads/podrocje/posebne_potrebe/pdf/Tabela_ucenci_s_posebnimi_potrebami.pdf (accessed 16. 10. 2020); Inštitut RS za socialno varstvo: Število romskih otrok glede na vrsto osnovnošolskega izobraževanja [Number of Roma children by type of primary education]. https://www.irssv.si/demografija-8/2013-01-11-18-12-72/stevilo-romskih-otrok-glede-na-vrsto-osnovnosolskega-izobrazevanja (accessed 16. 10. 2020).

We have stopped this activity in 2020 after the ECtHR decision due to lack of any, even minimal, interest by authorities.[6]

Unemployment rates are extremely high, but in our line of work we only received unofficial estimates because the state does not collect disaggregated data. In the Administrative unit Novo mesto area, officials usually use an estimate of over 90 % Roma unemployment, while some even claim 98 % unemployment rate (the unofficial information of the officials of the Novo mesto municipality for their municipality).

Underage pregnancies are common and not addressed systemically or in specific cases. I was personally involved in several cases; some can even be classified as forced marriages. These marriages are not formal; we are talking of sexual relationships really. In one of such cases the Police failed to intervene and find a minor who was »kidnapped« or – as the other side claimed – »escaped abuse by the father«. A special police unit was unsuccessfully seeking for this minor for over a week and a chief police officer involved in resolving the volatile situation. The Roma observed how impotent the authorities including the Police actually are. Naturally, the problem lies in both legislation and lack of proper horizontal cooperation on the national and local level of all institutions.

Access to water, sanitation and electricity is often non-existent.[7] There is some official information on the situation in Roma settlements, but these official lists often ignore illegal parts of otherwise legal settlements. The information is thus flawed. On the general level, estimate approximately 1,000–1,500 Roma do not have access to water. Roma collect water in cemeteries, petrol stations and even in (polluted) streams and forest springs. I have seen it all, as has the Ombudswoman dr. Čebašek-Travnik when we took her to one of these settlements (a surprise visit) in Škocjan. The Ombudsman special report on the situation of Roma from 2012[8] is very detailed in this

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[6] Amnesty International: False starts: The exclusion of Romani children from Primary education in Bosnia and Herzegovina, Croatia and Slovenia (2006). https://www.amnesty.org/download/Documents/76000/eur050022006en.pdf (accessed 16. 10. 2020).

[7] Amnesty International: Parallel lives: Roma denied access to housing and water in Slovenia (2011). https://www.amnesty.org/download/Documents/32000/eur680052011en.pdf (accessed 16. 10. 2020).

[8] Varuh človekovih pravic RS: Posebno poročilo o bivanjskih razmerah Romov na območju jugovzhodne Slovenije [Special report on the living conditions of Roma in

regard, as is completely ignored. Surprisingly, the ECtHR decision explicitly states it is in line with Human Rights standards if the public water access point is 1,8 kilometres away.

A special situation is linked to access to electricity, which is not a part of Human Rights yet. Some Council of Europe bodies state electricity as a basic necessity, but in legal proceedings in 2018 the Higher court in Ljubljana ruled against the lawsuit of the Roma to access electricity. When managing the case with Amnesty International attorney, we decided not to push the issue to the Constitutional court due to the poor chances of success.

Buildings of Roma are significantly sub-standard. In the past, the dwellings were often subject of forced removal attempts. I have personally managed a legal proceeding of a Roma from Škocjan, culminating in the Constitutional court decision U-I-64/14 from 2017, which effectively stopped all forced evictions in the country (not just for Roma; the implementing legislation has not been adopted yet). The court emphasizes, to simplify, no one's home should be demolished just because it is illegal. There are no additional support measures in place, like social housing and other measures in the Dolenjska region. Even more, I have also personally established an illegal Roma settlement (I actually advised against it, as had the attorney later, but the family simply had no choice), due to no other options possible, helping a family flee inter-community violence into the forest and for the lack of any social housing, helping them legalize a wooden hut to live in the forest (17 people reside there at this moment in 2020). Similar constitutional court motions on other bits of legislation and municipal zoning plans were not considered admissible by the court when challenging the material-law provisions of the Krško municipality in similar cases. It is worth noting that in 2015 the Catholic church sold a property with an illegal Roma settlement in Krško – with people included. None intervened despite being called to by NGOs and Roma representatives.[9]

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the area of south-eastern Slovenia] (2012). http://www.varuh-rs.si/fileadmin/user_upload/pdf/posebna_porocila/POSEBNO_POROCILO_ROMI_-_maj_2012_-_za_splet.pdf (accessed 16. 10. 2020).

[9] Marjan Jerman, Gorazd Rečnik: Prodaja romskega naselja: lastnina proti človekovim pravicam [Sale of a Roma settlement: property against human rights]. In: Val 202 (15. 7. 2015). https://val202.rtvslo.si/2015/07/romsko-naselje-rims-z-romi-se-bodo-zaceli-pogovarjati-po-koncanem-poslu/ (accessed 16. 10. 2020).

Social housing is simply not an option. Where municipalities have public tenders, in Dolenjska (Črnomelj, Novo mesto) they grant additional points for employed applicants and for higher levels of education. This effectively blocks Roma from receiving social housing, keeping them in their illegal ghettos on the outskirts of society. This is explicit discrimination, which the state authorities, Ombudsman and the Advocate of Equality fail to see, address and prevent. Inspection services fail to intervene.

Other issues arise from the marginalized position of this minority. Inter-community disputes are often and almost always encompassing entire families. In extreme cases of underage kidnappings or underage marriages and occasional extreme violence, state systems completely fail to react. Anecdotal are stories of Police unable to locate missing children on runaway-honeymoons or even kidnapped (sometimes children escaping from police cars), grotesque are examples of minors with two or even three children of their own already. In Ribnica, a minor gave birth to her third child – which was put into care by social services at the infirmary, apparently because of living in extremely substandard conditions. Her other two small children were left in her care as they were not endangered, though living without water and electricity. Her brother's third child died in the same period due to »the accidental death in the cradle«. In fact, the body was bitten by rats. The social services removed the other two children from this family temporarily. The families are not even registered in Ribnica and have lived in these extreme conditions for years. What this case implies as a possible solution is a massive removal of Roma children by authorities like in Australia.

In some areas, cultural ties to the majority are not present and due to the abovementioned failure of the educational system, the Roma in the south-east often live in a parallel society, have poor functional literacy, are sometimes actually illiterate and on the general level have actually poorer command of majority language.

Official information on life expectancy and mortality rates are disastrous, but which is not a surprise considering the living conditions. It's just that authorities do not care at all. Official information from the end of 2019 from National Institute of Public Health show that the life expectancy of Roma is just 55 years, 22 years less than the majority population (77 years). Roma baby mortality rates are four times higher than in majority population. The mortality rate of babies from the first to fourth years of age is seven times higher than in majority population.[10]

Criminal offences with prison terms even further worsen the social position of families. Because of local clashes, crimes and minor offences, the majority population often requests repressive action. I cannot comment on inter-community relations, but it's clear they are poor. Cases of extreme servitude dependencies, bordering on slavery, are known (I have chosen not to engage in one of these stories myself). Extortionate loans and drug trade, are common too.

The majority population is not to be automatically blamed – their living conditions are often poor too. Cases of attempted prohibition of burials, public protests of all sides, attempted forced evictions and general ignorance of institutions are often. Ignorant local politicians are often explicitly xenophobic, racist and thrive when politically aggressive against minorities.[11]

Public funding of activities (in some municipalities the rule is to provide nothing) usually means activities are not strategic and not measurable and are project based. I had seen project leaders and inclusion partners afraid to call the municipality lest they lost funding when it came to Roma issues, including the low vaccination rates of children who often become a medical risk (I was once detained in hospital for fear of mumps, by the way). On the other hand, the authorities often fund activities just for the sake of it, even if they are idiotic. Funding erotic half-naked children dancing as a cultural activity is one of these examples.

All these issues culminated in the abovementioned two cases at ECtHR. As said, our team raised a referral to the Grand Chamber (a complaint) to reopen the case. It is the only alternative to an escalating situation that would lead to law changes across the board and benefit the majority the most, to be honest. Why local politicians

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[10] Tatjana Krajnc Nikolić, Olivera Stanojević Jerković, Martin Ranfl, Damijan Jagodic, Jerneja Župan, Martina Copot, Victoria Zakrajšek, Zdenka Verban Buzeti: Public health approaches for the Roma ethnic community in Slovenia. Ljubljana 2020.

[11] Varuh človekovih pravic RS: Sistemska segregacija Romov v občinah [Systemic Roma segregation in individual municipalities] (16.10.2007). https://www.varuh-rs.si/obravnavane-pobude/primer/sistemska-segregacija-romov-v-posameznih-obcinah/ (accessed 21.10.2020); Gregor Cerar: Številni Romi še vedno živijo v nekakšnih socialnih getih [Many Roma still live in some kind of social ghetto]. In: MMC (8.4.2013). https://www.rtvslo.si/slovenija/stevilni-romi-se-vedno-zivijo-v-nekaksnih-socialnih-getih/306188 (accessed 16.10.2020).

remain ignorant and tolerate extreme poverty in some areas is beyond me. Why state institutions do not push for more targeted powers and opportunities also eludes me.

Unfortunately, we were not successful with our legal work.

3. Health care issues

In 2011 the Ministry of health compiled a collection of reports from local health centres and hospitals on the situation of Roma minority. This collection of reports can be obtained through the Ministry of health (for some reason it is not public) and does not include any analysis by the state, it just joins responses of local health institutions. Several Dolenjska health centres claim poor inoculation levels. Access to water, sanitation and electricity is often emphasized as a factor in relation to poor health conditions. Some institutions extend their competence and even focus on minority behaviour and other issues.

As already explained, the 2020 the National Institute of Public Health report is much more worrying with outrageous information on significantly lower life expectancy and higher infant mortality rates for Roma.

In the field, my interlocutors often claim diarrhoea, colds and other diseases – because of poor living conditions.

A woman, who gave birth to 15 (fifteen) children claims she never visited a gynaecologist. I believe her. Preventive sex education does not exist. Projects which were funded by the state in the Roma settlements, focused on measuring the level of blood sugar – not by local health workers, but by ones from Prekmurje (a distant region). I guess only the number of projects counts, not their impact. It is safe to say that there is no systemic approach by the health sector towards Roma because it is overburdened.

I have already mentioned underage pregnancies. The most critical few I faced in the field were minors, giving birth to children. In the last two such cases in the same family (in January 2020, before the ECtHR judgment), in one family there was a dead child, bitten by rats (other two removed to custody) and in the other family the authorities took custody of a newborn in the hospital the same day the child was born for being endangered – but not the child's siblings. Both mothers gave their first birth undragged, around 15 or 16 years of age. Other underage pregnancies follow the same pattern: underage, no basic infrastructure, no education of parents – no prospects for a future. Sometimes Roma pupils just quit school in order to start a family. The income expectancy in the short turn is greater. Except in those two cases, I have not witnessed any reaction of social institutions, even in the cases of extreme inter-community violence or alleged rape or sexual work accusation. I fear that even in these two cases, the state intervention will not resolve anything.

An anecdote from Grosuplje can show how it looks like in the field. I was helping the elected Roma municipal council member with legal issues. His predecessor had to win at Administrative court twice just to get his mandate confirmed. In one of the projects, managed by people in offices far away from the field, an idea came up to reach out to the local health centre to ease inoculation of preschool children and thus school integration. However – no one within the public sector (the school, kindergarten, project leaders) wanted to call the municipality or the health centre to discuss the issue or facilitate the process. The Roma council member and I set up a meeting, discussed the idea and implemented a visit of the most critical families in the health centre building. It was impossible to organize visits of health workers in the settlements due to medical standards and lack of capacity, which came to us as a surprise. I always thought that if one wants to address and resolve an issue, one must resolve it in the field, not in their offices far from the field. After this initiative, no official institution picked it up – and slowly the contact faded, especially after the Roma council member suffered a stroke.

The above story is symptomatic. On all issues, the problems are addressed in offices in Ljubljana. There, the situation is far from the eyes and far from the heart of the decision-makers. The same applies to local institutions – since many Roma settlements are hidden in the forests or behind industrial zones, they make no effort not to disturb the majority. How convenient.

Health care issues correlate to and with other challenges significantly and the society cannot tackle one issue without tackling them all. If we cannot as a society agree on this, there is absolutely no point in asking ourselves how to tackle them at all.

4. Conclusion

Writing of the paper was challenging and therapeutic at the same time because of all the efforts put forward in the past fifteen years. In practice, little has changed, and after the European Court's decision and the unsuccessful referral to the Grand Chamber, little is going to change in the next ten years. I have become very pessimistic about any prospects for a change, causing a shift of both my organization and my professional preference to other topics.

Now I feel that this paper is the real waste of the story, not just regarding Amnesty International Slovenia and my career because I will manage but for a group of people with learned and acquired knowledge, skills and competence on minority-related issues. The authorities, people in power-positions, including minority leaders or faculty professors, choose to ignore Roma people to pursue their personal or short-term interests. The gain of the few thus causes the loss or lack of progress for Roma, the vast majority and also the local majority population.

It is not the whining of a would-be individual. It is reality, controlled by what I call project mafia and key-decision-makers who want to keep their public-sector jobs. It's the easy way out. The authorities get an excuse of yearly amount of funds, diverted to various (impact-less) projects, to report to inter-governmental organizations, like Council of Europe or United Nations.

I have always asked my interlocutors a simple question, and I would like to share it with the readers here: What do we want the Roma minority to look like in 2050? Do we want over 60 % dropouts in primary schools, illiterate, unemployed, socially excluded with poor health, low life expectancy and trapped in their limited society, including informal power networks, underage pregnancies and a lifestyle of easy crime where almost no one pays taxes? If we are okay with that, well, Slovenia is doing just great, and nothing needs to change.

If that is not what we want, I propose to clean out the Augean stables of Roma (as Hercules did). In other words, to build a new house, you must first burn down the old one. There is no alternative. The whole system must change – or we will accept illiteracy in 2020 in Slovenia. In Slovenia, there is no Strategy on Roma integration with measurable goals, timeframes and funding in place (SMART –

specific, measurable, accountable, real timeframes).[12] There is a Roma strategy on education, but there are no measurable goals inside – like how many Roma children does the society want to finish primary school by 2050? This shows the attitude of authorities although some players, including the Parliamentary Commission for Human Rights called on the Government to create such a SMART strategy.

I wrote most of this article long before September 8, 2020. On that day, the Grand Chamber of the European Court of Human Rights rejected the complaint (the referral) of the two Roma families. It means that changes in the law are still years away (our proposals to change the law, which we worked out with judges, lawyers and other professionals, were forwarded several times to the authorities – we never received a reply). Unfortunately, I feel tired and hope I do not have to participate in this process again with the same decision-makers who are responsible for the situation and have been in their respected positions all these years, with ongoing challenges that do not seem to change one bit.[13]

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[12] Amnesty International: Public statement (2020). https://www.amnesty.org/download/Documents/EUR6819842020ENGLISH.PDF (accessed 16. 10. 2020).

[13] Amnesty International: Slovenia: Persisting challenges in Roma integration – Submission for the UN Universal Periodic Review (2019). https://www.amnesty.org/download/Documents/EUR6804762019ENGLISH.PDF (accessed 21. 10. 2020).

Mateja Lopuh

Social diversity and access to palliative care for minority groups

Abstract

Introduction: Palliative care is an approach in medicine that specifically addresses the needs of a patient with an incurable, progressive and life-limiting disease, as well as his proxies. It does not focus only to end-of-life care but provides possibilities of living a quality life with such a disease. Key demographic characteristics of the population that have been identified as influencing the need for palliative care are age, gender, ethnicity/religion, socioeconomic status and household composition.

Methods: Qualitative data were collected, using structured and semi structured interviews. Ten patients and their proxies were included in the study. Major points of palliative care were addressed. Descriptive statistics was used to analyse the collected data.

Results: Understanding the scope of palliative care, language barrier, resistance to using morphine and not identified differences at the end-of-life are the major obstacles, identified by all included patients.

Conclusion: Access to good palliative care should be made available to all patients having a palliative disease. Home setting, when possible, is a better choice for respecting cultural and ethnical differences.

1. Introduction

The increased prevalence of chronic illnesses in ageing population has led to an increasing proportion of people needing palliative care globally.[1] World Health Organisation called to incorporate palliative care

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[1] Simon N. Etkind, Anne E. Bone, Barbara Gomes, Natasha Lovell, Catherine J. Evans, Irene J. Higginson, Fiona M. Murtagh: How many people will need palliative care in 2040? Past trends, future projections and implications for service. In: BMC Medicine 15 (2017), pp 102–110.

in the health care system of member countries.[2] Even though access to palliative care is considered a human right in many countries, the percentage of people who actually do receive it, is considerably low, 14 %.[3] Palliative care is an approach that is focused on the patient and his needs, the major end-points being the quality of life and relief of symptoms. Individual needs of the patients constitute a framework in which palliative care is delivered to them. It should cover the physical, psychological, spiritual and social needs. General or basic palliative care is frequently delivered by non-specialists in a primary or secondary setting. Specialist multidisciplinary teams deliver care for more complex needs in a variety of settings and can also provide more straightforward end-of-life care.[4]

Palliative care covers the principle of total body assessment, developed by Dame Cicely Saunders. It also includes the proxies and extends into the phase of bereavement. Due to proper symptom control and good social support it enables good quality of life in spite of the presence of incurable disease.

There have been many factors identified to influence the need for palliative care: age, gender, ethnicity/religion, socioeconomic status and household composition from the patients' perspectives. Therefore, »(…) also healthcare providers sometimes find it challenging to address the palliative care needs of patients from different ethnocultural groups.«[5]

Health access and quality of treatment are not equal for racial and ethnic minorities. Approximately 20 % of older adults belong to racial or ethnic minority. There is growing evidence that disparities exist also in access to palliative care. The rate of usage of the palliative care structures such as hospices, home-care services or inpatients pal-

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[2] World Health Organization: Strengthening of palliative care as a component of comprehensive care throughout the life course. Report by the Secretariat A67/31. World Health Assembly, 67 (4.4.2014). https://apps.who.int/iris/handle/10665/158962 (accessed 22.12.2020).

[3] World Health Organization: Palliative care. Fact sheets (5.8.2020). https://www.who.int/news-room/fact-sheets/detail/palliative-care (accessed 1.12.2020).

[4] Etkind, Bone, Gomes, Lovell, Evans, Higginson, Murtagh: How many people (Note 1).

[5] David Busolo, Roberta Woodgate: Palliative care experiences of adult cancer patients from ethnocultural groups: a qualitative systematic review protocol. In: JBI Database of Systematic Reviews and Implementation Reports 13 (2015), pp. 99–111.

liative care consultations is consistently reported as lower in comparison to non-minorities.[6]

In Slovenia the Ministry of Health approached towards the organisation of palliative care by providing a national plan of palliative care development. According to the plan palliative care structures should be organised at each level of health system. As for all other healthcare services there is a two-level approach: basic palliative care, provided by non – specialists at all levels and specialized palliative care, provided by specially trained medical staff at secondary and tertiary level. There is possibility of referral at any stage of the disease, whenever the symptom control is more difficult, the social situation more complex or the spiritual and psychological issues more demanding. There is also a possibility to extend the specialized services into the community by mobile palliative care units.

After the first Action Plan in 2010–2016 many small steps have been taken but in general the major obstacle, identified by medical workers, which inhibits the proper development of palliative care in Slovenia, is the lack of interest in further education. Although there has been a possibility to expand knowledge by attending the 60 hours' postgraduate course in the skills of palliative care from 2011, only around 600 participants attended the course, with less than 10 % of all the licensed doctors in Slovenia. Ministry of Health therefore approved funds to include the 60 hours' course as a compulsory course in all clinical specialisations.

According to the collected data, there has been some organised palliative care in almost every Slovenian hospital but most of the structures are run, not by whole teams, but by enthusiastic individuals.[7]

In Gorenjska, one region in Slovenia, there has been the only one mobile palliative care unit in Slovenia, operating from 2011. It bridges the gap between hospital and home care. It is well known that the majority of patients prefer to die in their usual place of care. The mobile palliative care unit helps to fulfil such wishes. The num-

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[6] Kimberly S. Johnson: Racial and Ethnic Disparities in Palliative Care. In: Journal of Palliative Medicine 16 (2013), pp. 1329–1332.

[7] Državni program razvoja paliativne oskrbe [National Palliative Care Development Program] (2010). https://www.gov.si/assets/Ministrstva/MZ/DOKUMENTI/pomembni-dokumenti/47cbef2cb3/Drzavni-program-paliativne-oskrbe.pdf (accessed 29. 9. 2020); Slovensko Združenje Paliativne Medicine: Projekt Metulj [Butterfly Project]. http://www.paliativnaoskrba.si/o-projektu.html (accessed 29. 9. 2020).

ber of patients, included, has been steadily on rise; from 110 in 2011 to 650 in 2019.[8]

In Slovenia, immense efforts have been made to bring the idea of good palliative care into practice. Not much research has been done so far. Due to the lack of general understanding of the benefits of palliative care, not much attention could be paid to the ethnic and cultural differences of patients, widening the gap in the perception of palliative care as a useful approach for many patients. In Slovenia, there are around 83 % people of Slovenian nationality, there are more than 1 % of Bosnians, Croats and Serbs, around 8 % of people did not want to declare their ethnical or national origin.[9] Gorenjska is also a region with cultural and ethnical diversity. The longer tradition of delivering palliative care has made it possible to explore the possible differences between the ethnic and cultural groups. The major aspects of good palliative care were addressed and the differences in views noted.

2. Methods

Data were collected from patients and their proxies involved in palliative care through the mobile palliative care unit. Structured and semi-structured interviews were used to gain a better understanding of the palliative care experiences of patients and their proxies from different ethnic groups. »Ethnicity has been defined as distinctive shared origins or social backgrounds and traditions of a group of people that are maintained between generations and bring about a sense of identity that may encompass a common language and religion.«[10]

10 participants were included: five patients and five, by them identified, most important proxies: 3 Bosnian, one Croat, one Slovenian. Interviews were conducted at their homes during routine home visit. Three visits were analysed: first visit, second visit after two

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[8] Mateja Lopuh: Mobilna palliativna enota – vidik državne koordinacije [Mobile palliative unit – an aspect of state coordination]. In: 42. Srečanje Timov Družinske Medicine. Zbornik predavanj. Ljubljana 2016.

[9] European Commission: Slovenia: Prebivalstvo, demografsko stanje in jeziki. [Slovenia: Population, Demographic Situation, Languages and Religions]. https://eacea.ec.europa.eu/national-policies/eurydice/content/population-demographic-situation-languages-and-religions-77_sl (accessed 29. 9. 2020).

[10] Busolo, Woodgate: Palliative care experiences (Note 5).

weeks and last one before death. There should not be more than a week between the last visit and patient's death.

Some of the questions are regularly asked at scheduled visits: at first visit: the reason for referral to mobile palliative care unit assessment and quality of symptom control, using the Edmonton Symptom Assessments Scale (ESAS), proposed medication plan, special care needs. The consent to be cared at home has to be given at the first visit, possible exceptions have to be listed in the care plan. According to the course of the disease further topics are brought into discussion: preferred place of death, advanced care, funeral arrangements.

The questions were formulated such as: can you tell me, who referred you to mobile palliative care unit, why were you referred, etc. Sub questions could be used to further explain the answers given. Patients were made familiar with the use of ESAS.[11] It was required to fulfil the ESAS at every visit. The answers were noted in the plan of care immediately after the home visit. Plan of care is a part of patient's medical records, therefore no authorised person can access the data. The data were not collected specifically for this study; they are routinely collected by every patient. For this study, data from the included patients in the last month were chosen (May 2020).

3. Results

Among the included were five patients: two were men, three were female. Both men were taken care by their spouses, two females by their sons and by her spouse. All patients were diagnosed with advanced cancer; at the time of referral the disease has advanced to late stage with no specific treatment as an option available any longer. At the first home visit both were present: the patient and the proxy. The consent for home care was given. At that time no participant declared any barriers.

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[11] Cancer Care South East: Edmonton Symptom Assessment System (ESAS). http://cancercaresoutheast.ca/edmonton-symptom-assessment-system-esas (accessed 29.9.2020).

3.1 Symptom control

Patients reported their scores on symptom control scale. Typically, all women proxies scored higher than men. In the sense of symptom medication, all five patients were reluctant to take morphine, but not other opioids. The Bosnians stated that they were afraid to take it because the religion prohibits them to use addictive substances, the other two connected morphine with approaching end of life and were afraid to use, all believed in the possibility that morphine can hasten death. Only after explanation that morphine is the weakest drug of all opioid, they agreed to use it. No other drugs caused disagreement.

From proxies' view morphine was considered as the drug that may cause death. All were afraid that they might be accused of causing death although they understood that in the suggested dosage no such effect can be caused. With advanced symptom control in two of the patients, the subcutaneous pump was suggested to provide continuous infusion of drugs. It was considered a relief for proxies as they were not forced to administer that much medication anymore. In the course of the disease, every decline in patient status such are cognitive impairment or loss of appetite or constipation or vomiting were first attributed to prescribed drugs. Even after explanation that it is the disease not the medication that causes this decline, the Bosnian participants could not accept it. Other participants accepted this information.

> »Now you give me morphine, so I am about to die.«
>
> »Is it so far?«
>
> »With morphine I will only sleep.«
>
> »I believe he is like that because of all the medication.«
>
> »I know that he has to die. But do not kill him.«

3.2 Referral to palliative care

All patients were included by the treating specialist from our Oncology Institute in Ljubljana. They perceived this referral as the end point of their life. The Bosnian patients were very disappointed that the oncologist gave up and two of them sought second opinion. Their proxies included family members from abroad to provide additional aid. They felt that it was because of their nationality and poor language communication that it was not worth attempting further treatment. No one understood at first what is the aim of palliative care. The Bosnian and the Croat patients identified the language barrier when discussing the treatment option – no interpreter was offered to them and they felt they were missing something. The language barrier was exposed although all people have been living for more than 10 years in Slovenia.

The fear not to understand properly became important when more medication was included and this insecurity was a reason to ask for hospital admission when the disease advanced.

> »I am so sad that the doctors gave up on me.«
>
> »I believe they send me home to die.«
>
> »Palliative care is only about dying.«
>
> »Because I am just a worker they gave up. If I were more important, they would still find something.«
>
> »They told me something about you but I could not understand.«
>
> »You can come but leave me alone.«

3.3 Preferred place of care/death

All participants were willing to be cared for at home, they would often repeat they had enough of hospitals. All proxies were prepared for the care, men more often asked for support in nursing care. Only Slovenian patient considered transfer to a nursing home as a possibility, such transfer was not an option for Bosnian and Croat patients.

Except for Slovenian patient, the other four would like to die in the native land but were afraid to move there because of possible lack of medical support. They considered the level of medical help much more reliable in Slovenia.

The proxies were all reluctant to talk about death at the beginning, they all expressed doubts about their capability of care at the second visit. They were all offered additional help with a certified nurse, which was accepted only by Slovenian patient. Other families considered such help as an additional intrusion.

> »I do not want to go to the hospital anymore. I always had to wait for such a long time. There were so many people in the examination room. I could not hear properly.«

> »When I called for information, the doctor always spoke so quickly, that I could not understand. I was afraid, I was always missing something.«

> »I have a house in Bosnia. I built it with my hands. I shall never see it again.«

> »I have good friends here but my real people are in Bosnia. They know me and they will bury me according to our tradition.«

> »I do not know if he will listen to me and take the drugs properly. He accuses me of poisoning him.«

> »She is my wife; I will not allow any men touch her naked.«

3.4 Advanced care planning

None of the participants was willing to make an advanced care plan. They only wanted to discuss things in a timely manner. They were all afraid of planning ahead as the situation might change to better and they would lose some possibilities.

> »If I plan ahead and decide I do not want CPR and then I get hit by the car, would they not do it?«

3.5 Care of the body after death, funeral arrangements

Patients and their proxies were routinely asked about their wishes for funeral arrangements. Bosnian patients were afraid that autopsies would be performed. Very often it was mentioned that no respect was given to their traditional values at the hospital: undressing, toilet arrangements, praying possibilities. They were happy to be at home, so that they could follow their cultural aspects.

Spiritual part was poorly addressed. Although our service has no language barrier, it still lacks the knowledge about differences in perceiving death. It was suggested to include support from their own spiritual groups.

»Do you have to perform an autopsy? That will kill the soul.«

»Nobody ever asked me about myself. I could tell them what kind of person I was.«

»She wants to be buried in our way, dressed in a long dress.«

»Will you take away all the needles, so that she be again normal?«

4. Discussion

In Slovenia a lot of efforts have been put in the last 10 years in introducing the palliative care in the health system. Some of the options that such care enables: being at home, home visits by mobile palliative care unit, patient-centred care, including proxies, respecting values, dignity are so completely different and so new that more time is needed to make them acceptable and recognized by all stakeholders. With this struggle to make palliative care properly set in the health system, the needs of minorities tend to be overlooked.

Our study is a very small study but one of the first to expose the problem of cultural and ethnical diversity in Slovenia in palliative care. In Gorenjska region there is a big social diversity that will enable future research work in this field.

Although it is well documented that palliative care brings benefits in quality of life, there are still many obstacles to its utilisation. As McAtteer and Wellbery state, there is still a confusion about terminology, misperception about the intent and scope (only for terminal stage), that it can be administered only in centres or hospices rather than at home, fear that palliative care will deny the patient's life prolonging therapy. Many physicians are unfamiliar with disease development, prognostic indicator tools, and symptom control guidelines.[12] It is assumed that the concept of palliative care can be interpreted as desired. It has been suggested that palliative care should be incorporated into standard of care. The following strategies have been proposed: stating the prognosis at the first visit, appointing someone to ensure that advance directives are discussed, offering to discuss prognosis, coping strategies and goals of care at each transition.[13]

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[12] Rebecca McAteer, Caroline Wellbery: Palliative Care: Benefits, Barriers, and Best Practices. In: American Family Physician 88 (2013), pp. 807–813.

[13] McAteer, Wellbery: Palliative Care (Note 3).

In pursuing such a model, one should always keep in mind that the model is suitable for the majority but can have a great negative impact on minorities. Therefore, efforts must be made to conduct more studies on the topic and to encourage minorities to participate in such studies. Proper education of all stakeholders will promote the benefits of palliative care. Home based palliative care is a concept that follows the patients' wishes to be cared for and to die at home. Such care is associated with improved patients and family outcome, reduction in symptom burden and a more positive, satisfying experience.[14]

Special attention should be paid to the last days of life. The term end-of-life (EoL) does not have a proper definition yet. It may be referred to the very last days (one week to 10 days) before death or it can be understood even broader than palliative care itself.[15]

The study, published by Lan Fang et al., supports the findings in our study, considering the culturally and spiritually diverse groups. They performed a scoping interview and thematic analysis of article contents in 14 electronic databases. The search identified eight themes that need to be addressed: need for culturally and spiritually sensitive palliative care, impact of spiritual support on quality of life of terminally ill people, role of families in EoL decision making, EoL preferences by ethnicity and gender, diverse needs of hospitalized patients and applications for clinical practice, cultural competence and providers' values impacting healthcare decision making, interventions to inform and facilitate culturally sensitive EoL care.[16]

The influence of religious values and principles is found on both sides: health care providers and individuals approaching EoL. In our study, two spiritually different groups are included: Muslims and Catholics. Catholic is the main religion in Slovenia. Muslims are well connected in Jesenice and have good support among them, but

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[14] Barbara Gomes, Natalia Calanzani, Vito Curiale, Paul McCrone, Irene J. Higginson: Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. In: The Cochrane Database of Systematic Reviews 6 (2013), pp. 1–279.

[15] David Hui, Zohra Nooruddin, Neha Didwaniya, Rony Dev, Maxine De La Cruz, Sun Hyun Kim, Jung Hye Kwon, Christiana Liem, Eduardo Bruera: Concepts and Definitions for »Actively Dying«, »End of Life«, »Terminally Ill«, »Terminal Care«, and »Transition of Care«: A Systematic Review. In: Journal of Pain Symptom Management 47 (2014), pp. 77–89.

[16] Mei Lan Fang, Sixsmith Judith, Sinclair Shane, Horst Glen: A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping interview. In: BMC Geriatrics 16 (2016), https://doi.org/10.1186/s12877-016-0282-6.

somehow they do not trust or open up to people who do not belong to their religion.

This was also confirmed in a study by Gustafson and Lazeby. Many needs at the Eol of Muslim people are not properly addressed and remain unmet.[17] It is feared by some patients that the symptoms of advanced disease cannot be properly controlled. In the literature there is no such evidence. Having in mind patients' desire to be informed about the medication, the dosing schedule, the anticipated side effects, this allows the patient and his proxy to control the symptom in the most personal way: by the clock and on demand. One has to have in mind that proxies need to learn a lot about the drugs and the dosing intervals and the expected effects in a short period of time. Therefore, it is good to have some written material available. The proxy also takes the responsibility for administering the drugs.[18] In Slovenia there is no such authorisation for the proxies yet. It would though be good to have a document with which the proxies would be authorised to administer drugs by doctors' orders. Proxies play an important role in the care of the patient. They often are too protective, their stories intensify the symptoms, as seen in our Bosnian patients, or diminish them in order to present the patient in a better way.

Many physicians are reluctant to talk about the end of life. They fear that such conversations might deprive the patient of hope.[19] It is often considered one of the goals to discuss with the patient the end of life. One has to have in mind that the patient might not be willing to participate in such conversations. It is surprising that the conversation about funeral arrangement might be better accepted than the one about the end of life.

Providers of palliative care should have some insight in the ethno cultural specifics of their patients. Language barriers should not exist, interpreters should be used more often, especially when important topics are discussed. »When ethnocultural knowledge is lacking,

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[17] Carolina Gustafson, Mark Lazenby: Assessing the Unique Experiences and Needs of Muslim Oncology Patients Receiving Palliative and End-of-Life Care: An Integrative Review. In: Journal of Palliative Care 34 (2019), pp. 52–61.

[18] Eleanor Wilsonßb_bau4_bß, Glenys Caswell, Nicola Turner, Kristian Pollock: Managing Medicines for Patients Dying at Home: A Review of Family Caregivers' Experiences. In: Journal of Pain Symptoms Management 56 (2018), pp. 962–974.

[19] Sarah Brown: Why many doctors still find it difficult to talk about dying with patients. In: Canadian Medical Association Journal 191 (2019), https://doi.org/10.1503/cmaj.109-5691.

healthcare providers, especially those with minimal training on ethnocultural issues, may provide unsatisfactory palliative care.«[20]

In Gorenjska, there are strong ethnical society which advocate differences in needs. Sometimes their representatives are summoned to help with difficult issues. Several meetings have already been organised to help them understand the principles and the scope of palliative care.

As stated above our study is far too small to provide any concluding evidence. It is an observation of difference between ethnic groups that could have an impact on providing palliative care if not taken into consideration. A bigger study in all parts of Slovenia should be performed in the future.

5. Conclusion

Access to good palliative care should be made available to all patients with fatal illness. Communities and health care workers should be well informed about the benefits of such care. The main barrier to access to palliative care in our region is still the lack of understanding of its benefits, so that most palliative care is reduced to symptom control. Since there are no guidelines about respecting different cultural and ethnicity backgrounds, differences in needs are hardly taken into consideration. Home setting, when possible, is a better choice for respecting cultural and ethnical differences. The identified barriers in our study are similar with the ones that exist in the literature. Very important are considered the cultural differences between health care providers and persons, approaching EoL and their family members, language barriers, lack of awareness of cultural and spiritual diversity issues and lack of suitable information on EoL. It is necessary to learn about priorities in other cultures and to gain confidence. Therefore, the need for palliative care should be recognized early in the course of the disease and first contacts established before the symptom burden is too high. When poor understanding of the disease trajectory due to insufficient language command is an issue, an interpreter should be sought.

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[20] David Busolo, Roberta Woodgate: Palliative care experiences of adult cancer patients from ethnocultural groups: a qualitative systematic review protocol. In: JBI Database of Systematic Reviews and Implementation Reports 2015, pp. 99–111.

Ana Poščić, Adrijana Martinović

Gender identity and access to healthcare in Croatia – legal framework

Abstract

The Croatian Constitution guarantees every person the right to healthcare in accordance with the laws, as well as the right to healthy life. The practical realisation of the right to equal treatment in healthcare depends on having accessible healthcare facilities for everyone, without discrimination based on prohibited grounds, including gender identity and expression. These two grounds are explicitly recognised in the Croatian anti-discrimination legislation, and serve to protect and ensure equal access to healthcare services and health protection for transgender persons. The protection of intersex individuals is less explicit.

The evaluation of the existing regulatory framework reveals that it might be easier to access certain health services at the cost of public health insurance in connection with, or after the legal recognition of change of legal gender or living in another gender identity. Even though the legal and clinical framework concerning the recognition of sex change or living in another gender identity has significantly improved in recent years, there are no other rules in place to accommodate or recognise special needs of transgender or intersex persons in healthcare. In addition, accessibility of specific health services for transgender and intersex persons may be impeded by the lack of funding and non-transparent decision making.

1. Introduction

Access to healthcare is a multifaceted concept and depends on financial, organisational, social, cultural, ethical, legal, technological and other factors and capabilities shaping a particular healthcare system. Equity and equality in access to healthcare are important aspects of the right to health as a fundamental human right, as understood in various international human rights treaties and other legal instruments.[1]

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[1] Universal Declaration of Human Rights (1948); Constitution of the World Health

The international standards for access to healthcare are translated into national constitutions, laws, policies and other regulations. The Croatian Constitution guarantees every person the right to healthcare in accordance with the laws, as well as the right to a healthy life.[2] Every person has the right to health protection and the right to enjoy the highest attainable standard of health.[3] Equal treatment in realisation of the right to health protection and provision of health services of standardised quality and equal content are guaranteed to everyone,[4] and any violation of these rights can be sanctioned.[5] Elimination of discrimination is the essential requirement of the guarantee of equal access to healthcare. There are laws and regulations prohibiting discrimination based on protected characteristics, such as sex, age, ethnicity, etc. in various fields of public and private life, including the provision of health services.[6] This paper will explore these guarantees and standards in relation with the access of transgender and intersex persons to healthcare in Croatia. The question is how the existing national regulatory framework applies in clinical practice and whether it is appropriate for securing the equality of access.

This paper is structured as follows. We will first provide a short overview of the general legal framework for the protection against discrimination of transgender and intersex persons in Croatia, along with the standard definitions of the fundamental concepts (2.). We will then proceed with identifying and analysing the main legal instruments concerning access to healthcare for transgender and inter-

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Organisation (1946); International Covenant on Economic, Social and Cultural Rights (1966); Convention on the Elimination of all Forms of Discrimination Against Women (1979); Convention on the Rights of the Child (1989); European Social Charter (1961); Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (1997). See also United Nations, Economic and Social Council: The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc No. E/CN.4/2003/58, 13 February 2003, pp. 6–10.

[2] Ustav Republike Hrvatske [Constitution of the Republic of Croatia]. In: Narodne novine Nos. 56/1990, 135/1997, 113/2000, 28/2001, 76/2010 and 5/2014, Articles 58 and 69.

[3] Zakon o zdravstvenoj zaštiti [Health Protection Act]. In: Narodne novine Nos. 100/2018 and 125/2019, Article 5(1).

[4] Zakon o zdravstvenoj zaštiti (Note 3), Article 26(1)(1) and (3).

[5] Zakon o zdravstvenoj zaštiti (Note 3), Articles 242(1) and 245(1)(1) and (2).

[6] Zakon o suzbijanju diskriminacije [Anti-Discrimination Act]. In: Narodne novine Nos. 85/2008 and 112/2012; Zakon o ravnopravnosti spolova [Gender Equality Act]. In: Narodne novine Nos. 82/2008 and 69/2017.

sex persons (3.). In doing so, we first consider the special regulatory framework aimed at collecting necessary medical documentation for the change of legal gender (3.1.). We then move to the conditions for access to and funding of specific healthcare services (3.2.). In the following section, we briefly analyse the connection between the legal change of gender and access to health services (3.3.). Before concluding (5.), we will critically evaluate the existing regulatory framework to reveal its strengths and potential weaknesses (4.).

2. Transgender and intersex discrimination – general legal framework and definitions

2.1. *Definition of key concepts*

Since we will be focusing on the position of transgender and intersex persons in healthcare, we should first define these concepts. There is no legal definition of transgender and intersex in the Croatian legislation. In order to understand these terms, we rely on the definitions from the authoritative international instruments and guidelines, which are based on contemporary scientific knowledge and evidence.[7] Transgender is usually used as an umbrella term, an adjective referring to persons whose gender identity and/or gender expression differ from the sex/gender assigned to them at birth. This term encompasses various forms and descriptions used by persons whose gender identity crosses or transcends culturally defined gender categories, such as transsexual, gender-queer, gender-fluid, non-binary, cross-dresser, trans man, trans woman and others.[8] Intersex refers to an

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[7] Yogyakartaprinciples.org: The Yogyakarta Principles. Principles on the application of international human rights law in relation to sexual orientation and gender identity (2006). http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf (accessed 29. 9. 2020); Eli Coleman, Walter Bockting, Marsha Botzer, Peggy Cohen-Kettenis, Griet DeCuypere, Jamie Feldman, Lin Fraser, Jamison Green, Gail Knudson, Walter J. Meyer, et al.: Standards of Care for the Health of Transsexual, Transgender, and Gender- Nonconforming People. 7th Version. World Professional Organisation for Transgender Health (WPATH) 2012. https://www.wpath.org/publications/soc (accessed 1. 8. 2020).

[8] Coleman et al.: Standards of Care (Note 7), p. 97; Marjolein van den Brink, Peter Dunne: Trans and intersex equality rights in Europe – a comparative analysis. Luxembourg 2018, p. 34; Lucy Arora, Ralitsa Donkova, Hayley D'Souza, Evelyn Jager, Nathalie Meurens, Kate Regan, Sarah Vandenbroucke: Legal Gender Recognition in

experience of physical variance whereby individuals »cannot be classified according to the medical norms of so-called male and female bodies with regard to their chromosomal, gonadal or anatomical sex«,[9] which may be evident through primary and secondary sex characteristics. The principle of equality and non-discrimination in relation to these groups is primarily guaranteed under the protected characteristics of gender identity and gender expression. Gender identity is understood to refer to »each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth«,[10] while gender expression denotes an individual's presentation of gender through physical appearance, mannerisms, speech, behavioural patterns, names and personal references.[11] Gender identity is a wider term which includes gender expression as a ground of protection, but gender expression does not necessarily correspond to a person's gender identity.[12] Legislation in many European countries prohibits discrimination based on gender/sexual identity and/or gender expression.[13] In some jurisdictions, however, discrimination based on gender identity and expression is

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the EU: The Journey of Trans People towards Full Equality. Luxembourg 2020, pp. viii, 27; University of California, Davies Campus: LGBTQIA Resource Centre Glossary. https://lgbtqia.ucdavis.edu/educated/glossary (accessed 5. 7. 2020).

[9] Council of Europe, Commissioner for Human Rights: Human Rights and Intersex People: Issue Paper (2015), p. 13. https://book.coe.int/en/commissioner-for-human-rights/6683-pdf-human-rights-and-intersex-people.html (accessed 7. 8. 2020).

[10] Yogyakartaprinciples.org: The Yogyakarta Principles (Note 7), p. 6.

[11] Yogyakartaprinciples.org: The Yogyakarta Principles plus 10. Additional principles and state obligations on the application of international human rights law in relation to sexual orientation, gender identity, gender expression and sex characteristics to complement to complement the Yogyakarta Principles (2017), p. 6. http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf (accessed 7. 8. 2020).

[12] Yogyakartaprinciples.org: The Yogyakarta Principles plus 10 (Note 11), p. 6; Jens M. Scherpe (Ed.): The Legal Status of Transsexual and Transgender Persons. Cambridge 2015; Jens M. Scherpe, Anatol Dutta, Tobias Helms (Eds.): The Legal Status of Intersex Persons. Cambridge 2018; Konstanze Plett: Begrenzte Toleranz des Rechts gegenüber individueller sexueller Identität. In: Gunnar Duttge, Wolfgang Engel, Barbara Zoll (Eds.): Sexuelle Identität und gesellschaftliche Norm. Göttingen 2010, pp. 53–68; Luisa Lettrari, Manuel Willer: Aktuelle Aspekte der Rechtslage für intersexuelle Menschen. In: Maximillian Schochow, Saskia Gehrmann, Florian Steger (Eds.): Inter* und Trans*identitäten. Ethische, soziale und juristische Aspekte. Gießen 2010, pp. 257–278.

[13] Susanne Burri, Linda Senden, Alexandra Timmer: A Comparative Analysis of Gender Equality Law in Europe 2019. Luxembourg 2020, p. 13; Isabelle Chopin, Ca-

not explicitly recognised, but can be subsumed under the wide interpretation of sex as a protected anti-discrimination ground.[14] Sex characteristics, understood as each person's physical features relating to sex, have in recent years become more prominent and have been identified as another protected ground in international jurisprudence and literature. It is held that intersex discrimination is better covered under the protected ground of sex or sex characteristics, than gender identity or sexual orientation, since it refers to person's bodily characteristics.[15] Although there is no uniform approach, it is widely accepted that transgender and intersex persons are protected against discrimination either on grounds of sex, gender identity, gender expression or sex characteristics. However, the limit of protection depends on interpretation of these terms in national legal systems.[16]

Another term relevant for our discussion is gender dysphoria. It is a diagnostic category, used in the healthcare setting. It describes the (clinically significant) dissatisfaction or stress caused by incongruence between gender identity and sex assigned at birth (and gender role associated with that sex and/or primary and secondary sex characteristics).[17] For a long time, the term gender identity disorder was a diagnostic description used for classification of this concept in international taxonomies.[18] The American Psychiatric Association has

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therine Germaine: A Comparative Analysis of Non-Discrimination Law in Europe 2019. Luxembourg 2020, pp. 12–15.

[14] van den Brink, Dunne: Trans and intersex equality (Note 8), p. 47.

[15] European Union Agency for Fundamental Rights: Protection against discrimination on grounds of sexual orientation, gender identity and sex characteristics in the EU. Comparative legal analysis. Update 2015. Luxembourg 2015, pp. 70–71.

[16] United Nations: Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, UN Doc No. A/73/152, 12 July 2018, pp. 3–4.

[17] Norman M. Fisk: Gender dysphoria syndrome: The conceptualization that liberalizes indications for total gender reorientation and implies a broadly based multidimensional rehabilitative regimen. In: Western Journal of Medicine 120 (1974), pp. 386–391; Geoffrey M. Reed, Jack Drescher, Richard B. Krueger, Elham Atalla, Susan D. Cochran, Michael B. First, Peggy T. Cohen-Kettenis, Iván Arango-de Montis, Sharon J. Parish, Sara Cottle, Peer Briken, Shekhar Saxena: Disorders related to sexuality and gender identity in the ICD-11: revising the ICD-10 classification based on current scientific evidence, best clinical practices, and human rights considerations. In: World Psychiatry 15 (2016), pp. 205–221; Coleman et al.: Standards of Care (Note 7), p. 96.

[18] American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders. 4th Edition (DSM-IV); World Health Organisation: International Classifi-

replaced it in 2013 with the term gender dysphoria, to reduce the stigma associated with the term disorder.[19] However, gender dysphoria is still classified and diagnosed as a mental disorder (although gender non-conformity in itself is not sufficient for this diagnosis).[20] In ICD-10,[21] the gender identity disorder was categorised under the chapter on mental and behavioural disorders as well. The pathologizing of gender and sexual identities is heavily criticised, because it »reduces their identities to diseases, which compounds stigma and discrimination«.[22] Therefore, the ICD-11, which was adopted in 2019 and is supposed to be implemented by 2022, depsychopathologizes this diagnostic category and includes it in the new chapter on conditions relating to sexual health under the term »gender incongruence«.[23] The changes in classification are based on accumulated scientific, clinical, social, and human rights understandings and advances over the years with the aim of depsychopathologizing of diagnostic categories related to sexuality and gender identity, while still preserving access of transgender and intersex individuals to healthcare services.[24] The ICD-11 has still not been translated and applied in Croatia. However, the Croatian Professional guidelines for elaboration of opinion of health workers and psychologists on the establishment of conditions and requirements for sex change and living in another gender identity (hereinafter: the Professional guidelines)[25] willingly

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cation of Diseases (ICD-10 Version: 2019). https://icd.who.int/browse10/2019/en#/F60-F69 (accessed 1. 9. 2020).

[19] American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders. 5th Edition (DSM-V). https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/dsm-5-fact-sheets (accessed 1. 9. 2020).

[20] European Union Agency for Fundamental Rights: Protection (Note 15), p. 16.

[21] World Health Organisation: ICD-10 (Note 8).

[22] United Nations: Report of the Special Rapporteur on the right of everyone to enjoyment of the highest attainable standard of physical and mental health, UN Doc No. A/HRC/35/21, 28 March 2017, pp. 11–12; European Parliament: Resolution of 4 February 2014 on the EU Roadmap against homophobia and discrimination on grounds of sexual orientation and gender identity (2013/2183(INI)).

[23] World Health Organisation: International Classification of Diseases (ICD-11). https://icd.who.int/browse11/l-m/en#http%3a%2f%2fid.who.int%2ficd%2fentity%2f411470068 (accessed 1. 9. 2020).

[24] Reed et al.: Disorders related to (Note 17), p. 206; United Nations: Report (Note 16), pp. 5–6.

[25] Stručne smjernice za izradu mišljenja zdravstvenih radnika i psihologa o utvrđivanju uvjeta i pretpostavki za promjenu spola i životu u drugom rodnom identitetu [Professional guidelines for elaboration of opinion of health workers and psycholo-

depart from the concept of »gender identity disorder« and are entirely based on the concept of »gender dysphoria«. Even though the Professional guidelines were published in 2016, more than three years before the adoption of the new ICD-11, their drafters acknowledge the forthcoming reconceptualization of gender identity disorders in ICD-11.

2.2. The Croatian legal framework

The Croatian Constitution guarantees equality of all persons before the law.[26] Everyone in Croatia shall have rights and freedoms, regardless of race, skin colour, sex, language, political or other opinion, national or social origin, property, birth, education, social status or other characteristics.[27] This is a general equality provision with a non-exhaustive list of prohibited discriminatory grounds. Discrimination under Article 14(1) of the Constitution is not an independent legal basis for the constitutional complaint, and it has to be brought forward together with some other (material) constitutionally guaranteed right.[28] »Freedom, equal rights, national and gender equality, peacemaking, social justice, respect for human rights, the inviolability of ownership, the conservation of nature and the environment, the rule of law and a democratic multiparty system, are the highest values of the Croatian constitutional order and a ground for interpreting the Constitution.«[29]

The Anti-Discrimination Act is a horizontal act in the field of the prohibition of discrimination and the creation of equal opportunities, and includes an exhaustive list of prohibited discriminatory grounds: sex, race, ethnic origin, skin colour, language, religion, political or other opinion, national or social origin, property, trade union membership, education, social status, marital or family status, age, health, disability, genetic heritage, gender identity, expression and sexual or-

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gists on the establishment of conditions and requirements for sex change and living in another gender identity]. In: Narodne novine No. 7/16.

[26] Ustav Republike Hrvatske (Note 2), Article 14(2).

[27] Ustav Republike Hrvatske (Note 2), Article 14(1).

[28] Constitutional Court of the Republic of Croatia: U-III-3804/2010, para. 7; U-III-2325/2006, para. 6; U-III-3192/2003, para. 6.

[29] Ustav Republike Hrvatske (Note 2), Article 3.

ientation.[30] Therefore, transgender and intersex persons are protected against discrimination primarily under the characteristics of gender identity and expression from the Anti-Discrimination Act. The Anti-Discrimination Act has a very broad personal and material scope of application, as it applies to the conduct of all state, regional and local bodies, as well as all legal and natural persons, especially in (but not limited to) the fields of work and working conditions, education, science, sport, health protection, social security, justice and administration, housing, public media, access to goods and services, membership in trade unions, civil society organisations and political activities, and participation in culture and arts.[31] It regulates judicial protection in special anti-discrimination proceedings. In addition to the Anti-Discrimination Act, the Gender Equality Act is lex specialis in the area of gender discrimination.[32] The Gender Equality Act is specifically aimed at the protection and promotion of gender equality as a fundamental value of the Croatian constitutional order. It defines and regulates methods of protection against discrimination based on sex and establishment of equal opportunities for men and women.[33] Four of the grounds protected under the Anti-Discrimination Act, namely sex, marital status, family status and sexual orientation, are also protected grounds under the Gender Equality Act, but neither act specifically mentions transgender or intersex persons.

Croatia is an EU Member State, and its anti-discrimination legal framework is shaped in accordance with the EU anti-discrimination and equality law acquis, which includes primary and secondary EU law sources, as well as the case law of the Court of Justice of the European Union. There is no explicit reference to gender identity, gender expression or sex characteristics as protected grounds in the EU non-discrimination and equality legal framework.[34] The protection of transgender and intersex persons in EU law remains largely within the boundaries of sex discrimination, despite the fact that such

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[30] Zakon o suzbijanju diskriminacije (Note 6), Article 1(1).

[31] Zakon o suzbijanju diskriminacije (Note 6), Article 8.

[32] Zakon o ravnopravnosti spolova (Note 6).

[33] Zakon o ravnopravnosti spolova (Note 6), Article 1.

[34] Marcin Orzechowski, Marianne Nowak, Katarzyna Bielińska, Anna Chowaniec, Robert Doričić, Mojca Ramšak, Paweł Łuków, Amir Muzur, Zvonka Zupanič-Slavec, Florian Steger: Social diversity and access to healthcare in Europe: how does European Union's legislation prevent from discrimination in healthcare? In: BMC Public Health 20 (2020), https://doi.org/10.1186/s12889-020-09494-8.

an approach is not entirely fit for purpose.[35] Equal access to health services is guaranteed under the Council Directive 2004/113/EC of 13 December 2004 implementing the principle of equal treatment between men and women in the access to and supply of goods and services.[36] However, since this Directive relies on the binary perception of sex, the question is whether it would be capable of protecting transgender, and especially intersex persons from discrimination in access to health services.[37] Since gender identity and expression are expressly mentioned in the list of protected grounds under the Croatian Anti-Discrimination Act, it follows that the Croatian anti-discrimination legal framework establishes more explicit protections for transgender and intersex persons, than the EU legal framework.

3. Access to healthcare for transgender and intersex persons

The practical realisation of the right to equal treatment in healthcare depends on having accessible healthcare facilities for everyone, without discrimination based on prohibited grounds, including gender identity and expression.[38] Laws and regulations are instrumental in ensuring equal access. However, this does not just mean ensuring access to services typically available to the general population. Some of the health services are transgender or intersex specific, e. g. gender confirmation surgery, specific hormonal therapy, voice therapy, etc. Enjoyment of the highest attainable standard of health should include entitlements to these specific health services as well, based on medical need.

In this section, we will take a look at the main legal instruments and clinical guidelines developed in the context of the change of legal

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[35] van den Brink, Dunne: Trans and intersex equality (Note 8), pp. 46–49; Directive 2006/54/EC of the European Parliament and of the Council of 5 July 2006 on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation (recast). In: Official Journal of the European Union L 204 (26. 7. 2006), Recital 3.

[36] Directive 2004/113/EC of 13 December 2004 implementing the principle of equal treatment between men and women in the access to and supply of goods and services. In: Official Journal of the European Union L 373 (21. 12. 2004).

[37] van den Brink, Dunne: Trans and intersex equality (Note 8), p. 77.

[38] World Health Organisation: Sexual Health, Human Rights and the Law. Geneva 2015, p. 24.

gender and living in another gender identity. It is important to highlight that the change of legal gender and life in another gender identity in Croatia is possible even without submitting to gender confirmation medical procedures. Nevertheless, it is based on medical opinions by professionals experienced and trained in working with transgender persons. In order to facilitate this process, the previously mentioned Professional Guidelines with clinical instructions were developed and adopted in 2016.[39]

3.1. Legal recognition of gender: change of sex and living in another gender identity

The procedure of legal recognition of gender is regulated in the Act on State Registries[40] and the Ordinance on collection of medical documents and establishing conditions for change of gender and life in another gender identity (hereinafter: the Ordinance).[41] The gender label can only be changed from male to female and vice-versa, there is no option to abstain from expressing gender in the official registries and documents. There is no age limit, i. e. minors are also allowed to apply for the legal recognition of gender; their parents or caretaker have to co-sign the application. Self-determination is not sufficient for the change of legal gender in the Registry of birth and other official documents. A positive opinion of the National Health Council is required to obtain a formal decision of the competent administrative body allowing the registration of change of gender. The National Health Council is a special body comprised of nine distinguished medical professionals appointed by the Croatian Parliament at the proposal of the Minister of Health with the task of monitoring various areas of health protection, providing expert opinion in the field of planning, programming, and development, providing opinion in the process of the change of gender, as well as other important issues

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[39] Stručne smjernice (Note 25).

[40] Zakon o državnim maticama [Act on State Registries]. In: Narodne novine Nos. 96/1993, 76/2013 and 98/2019.

[41] Pravilnik o načinu prikupljanja medicinske dokumentacije te utvrđivanju uvjeta i pretpostavki za promjenu spola ili o životu u drugom rodnom identitetu [Ordinance on collection of medical documents and establishing conditions for change of gender and life in another gender identity]. In: Narodne novine No. 132/2014.

in the field of health.[42] The National Health Council issues the opinion on the basis of requisite medical documentation. The details on the method of collection of medical documentation, and requirements and conditions for the change of gender and living in another gender identity are prescribed in the Ordinance. The collection of medical documentation, and requirements and conditions for the change of gender and living in another gender identity are based on the principles of humanity in the protection of patients' rights, protection of the well-being and rights of a child, prohibition of discrimination and confidentiality of personal data.[43] No person shall be forced to undergo medical procedures, including gender confirmation surgery, sterilisation or hormonal therapy as a condition for recognition of the change of sex or living in another gender identity.[44] Everyone is guaranteed the right to respect of personal and family life in accordance with their own gender identity.[45] The requisite medical documentation includes an opinion of a psychiatrist, a clinical psychologist, and an endocrinologist. The specialists can provide their opinion jointly if they agree, or separately in cases of disagreement.[46] However, in order for their opinion to qualify for this procedure, the specialists must have experience and training in the field of health protection of transgender persons and must be included in the List of specialists adopted by the Minister of Health (hereinafter: the List).[47] The List includes specialists in the field of psychology, psychiatry, endocrinology, gynaecology, and surgery. In several fields (psychology, psychiatry, and endocrinology) there are different specialists for adult and children applicants. Out of 15 specialists included in the List, only two are not from Zagreb. Although it may be expected that highly specialised experts will be concentrated in the capital city, it nevertheless may have adverse impact on equal geographical distribution and accessibility of these services. Alternatively, a person may submit medical

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[42] Zakon o zdravstvenoj zaštiti (Note 3), Article 146(1).
[43] Pravilnik o načinu (Note 41), Article 2(1).
[44] Pravilnik o načinu (Note 41), Article 2(2).
[45] Pravilnik o načinu (Note 41), Article 2(3).
[46] Pravilnik o načinu (Note 41), Article 5(2).
[47] Lista stručnjaka koji imaju iskustva u radu s transrodnim osobama [The List of specialists with experience in working with transgender persons]. In: Narodne novine No. 59/2015.

documentation and opinion of foreign experts who have been monitoring the transition of the applicant in another country.[48]

In addition to the medical documentation, the report of the competent Social Welfare Centre about personal and family circumstances of the applicant has to be submitted to the National Health Council as well. The National Health Council is required to issue an opinion within 30 days from the day of receiving complete application and documentation.[49] If additional documentation is needed, a 30-day period is counted from the day of receiving that documentation, but the opinion has to be provided within the maximum of 60 days from receiving the application.[50] Even though there are no sanctions for violation of these time limits, their inclusion in the Ordinance is a welcome improvement in comparison to the previously applicable Ordinance from 2011 (hereinafter: the 2011 Ordinance).[51] The 2011 Ordinance did not contain any time limits in which the National Health Council had the obligation to adopt an opinion after receiving the application. This resulted in substantial delays in the procedure, because the National Health Council did not convene for very long time periods. The new Ordinance clearly stipulates the obligation of the National Health Council to convene in session within eight days after receiving the application.[52]

The National Health Council is not entirely bound by a finding and opinion of the specialists. If the finding or opinion is incomplete or unclear, if the findings and opinions of two or more specialists are contradictory, if the opinion is not sufficiently explained or there is reasonable doubt as to the correctness of the opinion, and these deficiencies cannot be remedied, the National Health Council shall request the finding and opinion of another expert from the List of experts, or the opinion of the health institution.[53] This will be rather difficult, or even impossible where only one specialist in a particular field is included in the List, such as in the field of endocrinology and

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[48] Pravilnik o načinu (Note 41), Article 5(4).

[49] Pravilnik o načinu (Note 41), Article 9(2).

[50] Pravilnik o načinu (Note 41), Article 9(6).

[51] Pravilnik o načinu prikupljanja medicinske dokumentacije te utvrđivanju uvjeta i pretpostavki za promjenu spola ili o životu u drugom rodnom identitetu [Ordinance on collection of medical documents and establishing conditions for change of gender and life in another gender identity]. In: Narodne novine No. 121/2011.

[52] Pravilnik o načinu (Note 41), Article 9(1).

[53] Pravilnik o načinu (Note 41), Article 9(3).

surgery. The opinion of the health institution may also be requested if, due to the complexity of the case, it is reasonable to expect that it might result in a joint opinion.[54] These provisions provide a considerable leeway for the National Health Council to intervene in the procedure.

The Ordinance provided an explicit basis for the elaboration of the Professional guidelines.[55] They were prepared by the specialists from the List and adopted by the Minister of Health. They rely primarily on the terminology and standards of care from the Standards of Care for the Health of Transsexual, Transgender, and Gender On-Conforming People (version 7) developed by the World Professional Association for Transgender Health (WPATH).[56] The Professional guidelines are accompanied by the Clinical instructions addressing the specific health issues of transgender and intersex persons. The Professional guidelines aim at standardisation and facilitation of the procedure for the preparation of an opinion on sex change and living in another gender identity. It is highlighted that protocolising of the procedure is necessary to protect transsexual and transgender persons from stigmatisation, non-professional and paraprofessional attitudes to which they may be exposed.[57] The need for an individualised and multidisciplinary approach is emphasised throughout the Professional guidelines. They are based on the understanding that the purpose of healthcare is to help individuals in a safe and efficient manner to attain continuous satisfaction with their gender identity, which will improve their general health condition, psychological well-being and self-fulfilment.

The Professional guidelines do not contain references to intersex persons at all. In addition to transgender persons, they refer to transsexuals. This is an older term used in medical and psychological communities,[58] which describes persons who seek to change or have already changed their primary and/or secondary sex characteristics by medical interventions (e.g. hormonal treatments, surgery), typically accompanied by a permanent change in gender role.[59] An intersex

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[54] Pravilnik o načinu (Note 41), Article 9(4).

[55] Pravilnik o načinu (Note 41), Article 6(1).

[56] Coleman et al.: Standards of Care (Note 7).

[57] Stručne smjernice (Note 25).

[58] Arora et al.: Legal Gender Recognition (Note 8), pp. viii, 28.

[59] Stručne smjernice (Note 25); Coleman et al.: Standards of Care (Note 7), p. 97.

variance remains largely invisible in the national context, as it is based on the binary perception of sexes.

The Clinical instructions are not binding. Their main purpose is to help the experts in providing adequate care. They highlight that the clinical approach to persons with gender dysphoria is anchored in contemporary scientific approach to health and psychosocial care, and should not depend on personal views of healthcare providers. The differences in gender identity and expression should be acknowledged and not pathologized, and the care provided in a manner which affirms gender identity and reduces the stress arising out of gender dysphoria. Patients should be given reliable, timely and scientifically based information about available treatments. Simple, accessible and appropriate healthcare services are based on informed consent and provided in accordance with individual healthcare needs in full acknowledgment of a person's preferred gender expression. The Clinical instructions stress the necessity of a continued care for an individual and his/her family and the readiness of specialists trained to work with gender non-conforming persons to support them and advocate their interests in their families and surroundings (schools, work, and other surroundings). This is an important expression of the overall approach implemented throughout the Professional guidelines which surpasses the merely medical function and is deeply rooted in ethical considerations. Detailed instructions on psychological and psychiatric, as well as endocrinological assessment and treatment are provided. Psychodiagnostic assessment of the psychologist and psychiatrist result in an opinion which is used for the application to the National Health Council, or as a gateway for further hormonal and/or surgical treatments. Further instructions on reproductive health and gynaecological care for transmen and transwomen who already had or are planning gender confirming surgery are specified. Gynaecological care should be provided according to the medical need and regardless of the sex registered in official documents. However, there are no instructions on surgical procedures, as they are not available in the Croatian health system.

The above presented framework for recognition of legal gender applies since 2014 and it is a welcome development in comparison to the previous situation. In the absence of clear and unequivocal legal provisions, the formal possibility to register a legal change of gender under the previous legal framework[60] was effectively obstructed in practice. It was practically impossible to change sex without the actual sex reassignment surgical procedure, even though it was never prescribed as a formal requirement for the change of legal gender. The reason for this partially lied in the attitude of the National Health Council that it cannot be determined for certain that an individual would not ›change his/her mind‹ about the change in cases where no gender reassignment surgery took place and when the change of gender is not ›irreversible and complete‹.[61] The turning point which resulted in the development of clearer legal framework and professional guidelines came in 2014, with the ground-breaking Decision of the Constitutional Court,[62] concerning a minor applicant whose legal battle to have his preferred sex and name registered in the Registry of births started in 2010. The Constitutional Court found that the constitutional guarantees regarding the duration of legal proceedings and the right to personal life and privacy, including the right to live in another gender identity were infringed in this case. The importance of the Constitutional court's decision in this matter lies in the fact that the court definitely put an end to arbitrary interpretation of the existing legal framework, but it also accelerated the adoption of the new, more efficient regulatory framework, which is presently applicable.

We now turn to the issue of access to and funding of specific healthcare services and the application of this regulatory framework in practice.

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[60] Naputak za provedbu Zakona o državnim maticama i upisu posvojenja u maticu rođenih [Directive for implementation of the Act on State Registries and registration of adoption in the Registry of Births]. In: Narodne novine No. 26/2008.

[61] Constitutional Court of the Republic of Croatia: U-IIIB/3173/2012, Decision of 18 March 2014, para. 3; Ombudsperson for Gender Equality: Annual Report for 2013, Annual Report for 2014, Annual Report for 2015. https://www.prs.hr (accessed 1. 9. 2020).

[62] Constitutional Court of the Republic of Croatia: U-IIIB/3173/2012, Decision of 18 March 2014.

3.2. Access to and funding of specific healthcare services

Full realisation of the right to health is contingent upon the availability of adequate, equitable and sustainable financing for health.[63] There is a substantial gap between the recognition of the need for transgender specific healthcare services and the available funding for such services.[64] Healthcare services related to gender transition may include hormonal therapies, surgical procedures, psychological counselling, permanent hair removal, voice therapy, use of prosthetic medical devices. Surgical procedures may include genital surgery, operation of the internal reproductive organs, breast augmentation and mastectomy, aesthetic surgery (such as face and body traits, or reduction of thyroid cartilage).[65]

The right to health protection, as one of the rights arising out of mandatory health insurance in Croatia, is guaranteed to every insured person under equal conditions.[66] Insured persons participate in covering healthcare services to a limited amount, and many healthcare services are covered entirely by the Croatian Health Insurance Institute.[67] Some health services are not covered from the mandatory health insurance, such as therapeutic and diagnostic procedures and medicines applied at the request of an insured person, experimental treatment, or aesthetic surgery (with limited exceptions).[68]

The Professional guidelines contain clear instructions about the necessary care for transgender and transsexual persons, including a flowchart of different procedures and treatments to be provided, with indications whether the treatment is available with or without diagnostic, and whether obligatory referral by a specialist is needed.[69]

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[63] United Nations: Interim report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc No. A/67/302, 13 August 2012, p. 3. https://documents-dds-ny.un.org/doc/UNDOC/GEN/N12/461/01/PDF/N1246101.pdf?OpenElement (accessed 23.10.2020).

[64] United Nations: Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, UN Doc No. A/74/181, 17 July 2019, pp. 5, 7. https://undocs.org/pdf?symbol=en/A/74/181 (accessed 23.10.2020).

[65] Stručne smjernice (Note 25), Flowchart 2.

[66] Zakon o obveznom zdravstvenom osiguranju [Mandatory Health Insurance Act]. In: Narodne novine Nos. 80/2013, 137/2013 and 98/2019, Article 19(1).

[67] Zakon o obveznom (Note 66), Article 19(2–4), Article 35.

[68] Zakon o obveznom (Note 66), Article 34.

[69] Stručne smjernice (Note 25), Flowchart 2.

However, the rules on funding of healthcare services have significant implications on the accessibility of healthcare services for transgender and intersex persons. Certain surgical procedures which may be part of the gender confirming healthcare are not performed in Croatia (genital surgery). Moreover, the general approach is that genital surgery is considered as aesthetic surgery and there is no possibility to obtain that type of care abroad at the expense of the mandatory health insurance either.[70] Many other surgical procedures, such as mastectomy and breast augmentation, are also considered as aesthetic surgical procedures which are not covered from the mandatory health insurance.[71] While it is true that many transgender persons do not submit to full medical transition and adaptation of primary and/or secondary sex characteristics, at least some do, and these limitations clearly obviate the proclaimed individual approach to the treatment of gender dysphoria.

Other issues concerning funding are associated with the fact that publicly funded hormonal therapy or medical devices (which are included in the basic list of medicines or medical devices and covered entirely from the mandatory health insurance) may be of inferior quality to those available under co-payment scheme (additional or supplementary list) or not refundable at all.[72]

On the other hand, storing sperm, egg cells or embryos before resorting to hormonal therapies or surgical treatment, in accordance with the conditions prescribed under the Croatian Act on medically assisted fertilization is funded from the mandatory health insurance.[73] The Clinical instructions also recommend that regular gynaecological care, if fully covered from the mandatory health insurance, should be provided to transwomen and transmen, depending on the scope and type of treatment they were submitted to, regardless of the legal gender in the official documents. By analogy, access to any other medical treatment, such as breast cancer screening, should be guaran-

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[70] Stručne smjernice (Note 25), Flowchart 2.

[71] Ombudsperson for Gender Equality: Annual Report for 2019, Zagreb, 2020, pp. 167–168; TransAid: Annual Report for 2019. Zagreb, 2020. http://transaid.hr/wp-content/uploads/2020/09/2019_Izvjestaj-o-radu.pdf (accessed 15. 9. 2020).

[72] TransAid: Mogućnosti u Hrvatskoj [Possibilities in Croatia]. http://transaid.hr/mogucnosti-u-hrvatskoj/ (accessed 15. 9. 2020).

[73] Zakon o medicinski potpomognutoj oplodnji [Act on Medically Assisted Fertilization]. In: Narodne novine No. 86/2012.

teed in accordance with the medical need, regardless of the legal gender of the person.

3.3. *The relation between the legal change of gender and access to health services*

As we have seen, the legal recognition of gender change or living in another gender identity is not based on self-determination, but requires specialist medical opinions and a positive opinion of the National Health Council. However, the link between the regulatory framework for the legal change of gender and living in another gender identity, on one side, and access to health services, on the other, seems too rigid. The procedure is the same, even if a person does not want to change legal gender, or at least not at that particular point in time. For example, in order to access hormonal treatment they will have to follow the path set in the Professional guidelines and Clinical instructions.[74] This means that it will not be possible to start hormonal therapy without the referral, which results from the psychodiagnostic evaluation by a psychiatrist and a psychologist. Currently, the diagnosis of gender dysphoria (gender identity disorder under ICD-11) is necessary for hormonal therapy. On the other hand, a person will not have necessarily already started with the hormonal therapy, or willing to start it, before or during the process of the legal gender recognition. Nevertheless, the opinion of an endocrinologist is a required medical documentation to be submitted with the application to the National Health Council.

The conclusion which necessarily arises from the above considerations is that it might be easier to access certain health services at the cost of public health insurance in connection with, i.e. after the legal recognition of either the change of legal gender or living in another gender identity. However, legal recognition in such cases should be seen as a barrier to access. There is also the risk that transgender persons may be »overdiagnosed« and subjected to extensive medical examinations, especially psychodiagnostics,[75] which is not necessarily required under the Ordinance and intended by the Professional guidelines.

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[74] TransAid: Annual Report (Note 71).

[75] TransAid: Annual Report (Note 71).

4. Evaluation of the existing regulatory framework

Apart from the legal and clinical framework concerning the recognition of sex change or living in another gender identity, there are no other rules in place to accommodate or recognise the special needs of transgender or intersex persons in healthcare. The general rules on equality of access apply. This may entail numerous practical deficiencies, especially when it comes to specific medical procedures designated for persons of a particular sex, or medical procedures which are usually provided only to persons of a certain sex. The EU equality law framework does not offer appropriate solutions for these situations. The Directive 2004/113/EC specifically provides that the differences between men and women in the provision of healthcare services, which result from the physical differences between men and women, do not relate to comparable situations and therefore, do not constitute discrimination.[76] The Croatian Anti-Discrimination Act, as we have shown, is more accommodating and explicitly prohibits discrimination based on gender identity and expression.[77] However, implementation of equality law standards requires a comparator.[78] The question remains, who would be a suitable comparator in such cases? Will transgender women be compared with cisgender women when it comes to access to certain healthcare services (such as breast implants, mastectomy, gynaecological examinations and treatments), or will they legally be considered male and be denied such access? Where a person changes legal gender, will they be left out of, for example, preventive screening programmes (such as breast cancer screening or prostate examination), even where they should be entitled to them based on their biological sex characteristics? Even though the right to health protection should be based on medical necessity,[79] it is likely that transgender and intersex persons could suffer adverse consequences in access to and financing of healthcare services, especially if a certain service is considered as unnecessary for the treatment. For example, after years of inconsistent practice where financing of mastectomy was dependent on individual assessments of specialists, in 2017 the Croatian Health Insurance Institute completely stopped fi-

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[76] Directive 2004/113/EC (Note 36), Recital 12.

[77] Zakon o suzbijanju diskriminacije (Note 6), Article 1.

[78] van den Brink, Dunne: Trans and intersex equality (Note 8), pp. 81–82.

[79] Zakon o zdravstvenoj zaštiti (Note 3), Article 5(1).

nancing mastectomy to transmen without explanation.[80] A possible reason for this might be that it is considered an aesthetic surgery, which is not covered from the mandatory health insurance.[81]

Available research shows that many trans individuals might refrain or delay seeking general care because of their gender identity, which results in poor health outcomes.[82] Prejudice from healthcare providers or a lack of confidence in healthcare services are among the main reasons which effectively discourage trans individuals from accessing health services. The position of intersex individuals could be even worse, because they are practically invisible under the existing regulatory framework. In Croatia, health workers in general have a very modest knowledge of transgender issues and in many cases their treatment towards transgender persons is guided by their personal views and attitudes.[83] The Professional guidelines attempt to overcome some of these shortcomings. However, they are strongly tied to the legal recognition of gender change, which results in the same legal requirements applying for access to healthcare services, whether a person wishes to change legal gender or not.

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[80] TransAid: Annual Report (Note 71); Ombudsperson for Gender Equality: Annual Report for 2019 (Note 71), p. 167.

[81] Zakon o obveznom (Note 66), Article 34.

[82] World Health Organisation: Sexual Health, Human Rights and the Law. Geneva 2015, p. 23; Adam Smiley, Aisa Burgwal, Carolina Orre, Edward Summanen, Isidro García Nieto, Jelena Vidi, Joz Motmans, Julia Kata, Natia Gvianishvili, Vierge Hård, Richard Köhler: Overdiagnosed but Underserved? Trans healthcare in Georgia, Poland, Serbia, Spain and Sweden: In: Transhealth survey 2017, p. 5. https://tgeu.org/wp-content/uploads/2017/10/Overdiagnosed_Underserved-TransHealthSurvey.pdf (accessed 15. 8. 2020); United Nations: Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, UN Doc No. A/HRC/38/43, 11 May 2018, p. 10. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/132/12/PDF/G1813212.pdf?OpenElement (accessed 23. 10. 2020); Arora et al.: Legal Gender Recognition (Note 8), pp. 145–151; European Agency for Fundamental Rights: Being trans in the EU: Comparative analysis of EU LGBT survey data. Luxembourg 2014, pp. 41–42; Bryony Whitehead: Inequalities in Access to Healthcare for Transgender Patients. In: Links to Health and Social Care 2 (2017), pp. 63–76; Joshua D. Safer, Eli Coleman, Jamie Feldman, Robert Garofalo, Wylie Hembree, Asa Radix, Jae Sevelius: Barriers to Health Care for Transgender Individuals. In: Current Opinion in Endocrinology, Diabetes and Obesity 23 (2016), pp. 168–171.

[83] Nataša Jokić-Begić, Anita Lauri Korajlija, Tanja Jurin: Psychosocial adjustment to sex reassignment surgery: a qualitative examination and personal experiences of six transsexual persons in Croatia. In: World Scientific Journal (2014), https://doi.org/10.1155/2014/960745.

The Ordinance on legal recognition of gender change was a welcome development after years of insecurity, because it had provided, for the first time in the Croatian legal setting, clear and explicit guarantees that no person shall be forced to undergo medical procedures, including gender reassignment surgery, sterilization, or hormonal therapy, as a condition for recognition of change of sex or living in a different gender identity. It has substantially contributed to the transparency, accessibility and acceleration of the procedure before the National Health Council.[84] However, further guidelines are needed to fully implement the guarantee of equality of access in clinical practice.

5. Conclusion

Croatia has a solid equality law framework, with explicit guarantees for the protection of transgender individuals against discrimination, based on prohibited grounds of gender identity and expression. It is based on and arises from the EU equality law acquis. Its material scope of application is wide and encompasses access to healthcare services and health protection. However, the position of intersex individuals is not quite unequivocal. They can rely on wide interpretation of gender, gender identity and expression as protected grounds, even though the prohibition of discrimination based on sex characteristics – which is still not expressly recognised in the Croatian laws – would be more appropriate for their protection.

Three main conclusions may be drawn. First, neither legal recognition of gender should be contingent on medical interventions, nor should access to healthcare be contingent on legal requirements. Under the current regulatory framework, the relation between the legal requirements for the change of legal gender, on one hand, and access to healthcare services, on the other, seems blurred. It seems that in clinical practice the same requirements for access to healthcare services apply, regardless whether a person is going through the process of legal change of gender or not. Extensive medical documentation is still necessary for the change of legal gender, and professional guidelines with clinical instructions were developed to facilitate this proce-

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[84] Ombudsperson for Gender Equality: Annual Report for 2019 (Note 71), pp. 166–167.

dure. Even though they are developed and follow the contemporary standards of care, their application in practice may lead to over-medicalization and further stigmatisation of transgender and intersex individuals.

Second, accessibility of specific health services for transgender and intersex people may be significantly impeded by the lack of funding from the mandatory health insurance. The crucial question here is what is considered a medical necessity and which healthcare services are essential for the treatment. Further clarity and transparency in financing decisions from the Croatian Health Insurance Institute is needed.

Third, no matter how developed the legal framework may be, education and sensibilisation of health providers for transgender and intersex issues is paramount for its proper implementation in practice.

II. Migration

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Improving the quality of care for a culturally diverse population: Understanding immigrant women's hospital experiences

Abstract

The European Union has seen a marked rise in immigration over the last decade. The study aims to describe the nature of health problems for which immigrant women most often seek medical help and explore their health system/healthcare professional experiences and their perception of the level of integration of culture in the care delivered. A mixed methods research design was used. The quantitative part included 52 immigrant women hospitalised in a single Slovenian hospital for female diseases and obstetrics between March and September 2018. The data were collected using a semi-structured questionnaire. The qualitative part was based on a descriptive-interpretative approach which encompassed a purposive sample of five immigrant women with experience of the Slovenian healthcare system. The data were gathered in 2018 with a semi-structured, one-to-one interview. Immigrant women most often sought help in a healthcare institution due to gynaecological problems, fever/infectious diseases and injuries. One of the greatest problems affecting the quality of medical treatment in everyday clinical practice perceived by the immigrant women was the language barrier and gender issues, especially concerning the provider. The integration of cultural concepts into healthcare should occur on systemic and operative levels.

1. Introduction

Migration is increasing around the world. People move to high-income countries for a variety of reasons. Individuals usually emigrate to improve their socio-economic status (labour migration), for study reasons or to seek family reunification, although a significant share of them are also forced to migrate due to war, human rights violations or persecution.[1] In the last decade, the European Union (EU) has con-

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[1] Trine Filges, Edith Montgomery, Marianne Kastrup, Anne-Marie K. Jørgensen: The

fronted a significant rise in immigration from outside the continent, leading to a growing ethnically diverse population in many EU member states. Data for 2015 indicate that approximately 54 million immigrants are living in the EU, making up almost 10.4 % of the total population.[2] While it is generally believed that the majority of immigrants are male, data for 2018 show that women account for around 46.0 % of international migrants in EU-27 member states,[3] showing that the migration of women is an important element of international migration.

There is a general consensus that migrant women are a particularly vulnerable group that should be guaranteed early access to the healthcare system.[4] However, unequal access to health services between migrant women and the host population are reported around the globe.[5] The literature[6] shows that migrant women face delayed access to screening (e. g. mammograms and cervical cancer screening), treatment and care (regular check-ups to help prevent, detect and treat diseases like heart disease, cancer and diabetes), have limited access to family planning (contraception and pregnancy termination)

Impact of Detention on the Health of Asylum Seekers: A Systematic Review. In: Campbell Systematic Reviews 11 (2015), pp. 1–104; Nicole C. Schmidt, Vanessa Fargnoli, Manuella Epiney, Oliver Irion: Barriers to Reproductive Health Care for Migrant Women in Geneva: A Qualitative Study. In: BMC Reproductive Health 15 (2018), https://doi.org/10.1186/s12978-018-0478-7.

[2] Vivian Graetz, Brend Rechel, Wim Groot, Marie Norredam, Milena Pavlova: Utilization of health care services by migrants in Europe-a systematic literature review. In: British Medical Bulletin 121 (2017), pp. 5–18.

[3] Eurostat: Migration and Migrant Population Statistics (2020). https://ec.europa.eu/eurostat/statistics-explained/pdfscache/1275.pdf (accessed 5. 9. 2020).

[4] Ines Keygnaert, Aurore Guieua, Gorik Oomsab, Nicole Vettenburgc, Marleen Temmermana, Kristien Roelensa: Sexual and Reproductive Health of Migrants: Does the EU Care? In: Health Policy 114 (2014), pp. 215–225; Zelalem B. Mengesha, Janette Perz, Tinashe Dune, Jane Ussheret: Refugee and Migrant Women's Engagement with Sexual and Reproductive Health Care in Australia: A Socio-Ecological Analysis of Health Care Professional Perspectives. In: PLoS One 12 (2017), https://doi.org/10.1371/journal.pone.0181421.

[5] Céline Ledoux, Eva Pilot, Esperanza Diaz, Thomas Krafft: Migrants' Access to Healthcare Services within the European Union: A Content Analysis of Policy Documents in Ireland, Portugal and Spain. In: Globalization and Health 14 (2018), https://doi.org/10.1186/s12992-018-0373-6; Schmidt, Fargnoli, Epiney, Irion: Barriers to Reproductive (Note 1).

[6] Filges, Montgomery, Kastrup, Jørgensen: The Impact of Detention (Note 1); Keygnaert, Guieua, Oomsab, Vettenburgc, Temmermana, Roelensa: Sexual and Reproductive Health (Note 4).

and are at greater risk of sexually transmitted infections. The reasons for these health inequalities between migrant women and the host population are multifactorial and hence quite complex. The main reasons for such inequalities are identified as language barriers and general communication problems between healthcare professionals and patients, lower health literacy, the low multicultural competence of healthcare providers, negative attitudes and low trust between healthcare professionals and patients, higher socio-economic stressors among migrant women/minority groups, difficulties in providing care for undocumented migrants, and issues arising during hospitalisation.[7]

Research on migrant women's experiences continues to show that healthcare providers lack awareness of such women's existence while the expectations between women and healthcare professionals are often uneven due to differences in culture.[8] Recognising the factors that might contribute to inequalities in the way migrant women are treated may help healthcare professionals in their efforts to make sure that women receive culturally appropriate care.[9] Culturally competent care is defined as a patient-centred approach that respects the diversity in the patient population and the cultural factors able to influence health and healthcare, such as language, beliefs, values, attitudes and behaviour.[10] Health systems that do not address cultural

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[7] Anna Bonmatí-Tomás, Maria del Carmen Malagón-Aguilera, Cristina Bosch-Farré, Sandra Gelabert-Vilella, Dolors Juvinyà-Canal, Maria del Mar Garcia Gil: Reducing Health Inequities Affecting Immigrant Women: A Qualitative Study of Their Available Assets. In: Globalization and Health 12 (2016), https://doi.org/10.1186/s12992-018-0373-6; Paola O. Ikhilor, Gabriele Hasenberg, Elisabeth Kurth, Fana Asefaw, Jessica Pehlke-Milde, Eva Cignacco: Communication Barriers in Maternity Care of Allophone Migrants: Experiences of Women, Healthcare Professionals, and Intercultural Interpreters. In: Journal of Advanced Nursing 75 (2019), pp. 2200–2210; Sandra Peláez, Kristin N. Hendricks, Lisa A. Merry, Anita J. Gagnon: Challenges Newly-Arrived Migrant Women in Montreal Face When Needing Maternity Care: Health Care Professionals' Perspectives. In: BMC Globalization and Health 13 (2017), https://doi.org/10.1186/s12992-016-0229-x; Schmidt, Fargnoli, Epiney, Irion: Barriers to Reproductive (Note 1).

[8] Ikhilor, Kurth, Asefaw, Pehlke-Milde, Cignacco: Communication Barriers in Maternity (Note 7).

[9] 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.

[10] Jacqueline McKesey, Timothy G. Berger, Henry W. Lim, Amy J. McMichael, Abel

diversity within healthcare institutions find it hard to provide culturally appropriate and congruent care.

The study aims to describe the nature of the health problems for which immigrant women most often seek medical help while exploring their health system and healthcare professional experiences together with their view on the level of integration of culture into the care delivered.

2. Methods

A mixed methods research design was used. This research approach requires a purposeful mixing of methods in data collection, data analysis and interpretation of the evidence. Mixed methods research exploits the potential strengths of both qualitative and quantitative methods and allows researchers to explore the different perspectives and relationships that exist between the complicated layers of the multiple research questions. This approach is often used in healthcare these days due to the internationally growing complexity of healthcare delivery.[11]

The quantitative part is based on a survey comprising a convenience sample of 52 migrant women hospitalised in one Slovenian hospital for female diseases and obstetrics between March and September 2018. Only adult migrant women over the age of 18 were included in the survey, and participation in the study was voluntary. Data were collected by means of a semi-structured questionnaire developed by the University of Trieste in collaboration with Burlo Garofolo Paediatric Institute. The Italian version of the questionnaire was translated into Slovenian and adapted to the Slovenian cultural context by a panel of experts in the field of health and sociology, and coordinated with the existing health system in the Republic of Slovenia. In addition to the socio-demographic part, the questionnaire contained 69 items concerning the social integration of migrant women in the host country and their sexual and reproductive health. Relevant is-

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Torres, Amit G. Pandya: Cultural Competence for the 21st Century Dermatologist Practicing in the United States. In: Journal of the American Academy of Dermatology 77 (2017), pp. 1159–1169.

[11] Allison Shorten, Joanna Smith: Mixed Methods Research: Expanding the Evidence Base. In: Evidence-Based Nursing 20 (2017), pp. 74–75.

sues were analysed only for the purposes of this paper. The participants' confidentiality and anonymity were guaranteed and maintained during the completion and return of the questionnaire. All participants were informed about the objectives, guidelines and study methods. The quantitative data were analysed using univariate descriptive statistics. The data were processed and analysed using SPSS version 23 (SPSS Inc., Chicago, IL, USA). For topics where open questions were used, the respective word units were ranked and presented according to the frequency of their occurrence.

The qualitative part was based on a descriptive-interpretative approach which included a purposive sample of five immigrant women with experience with the Slovenian healthcare system. Qualitative descriptive designs tend to be methodologically eclectic and based on the general premises of constructivist inquiry.[12] Interpretativeness in this approach requires integrity of purpose from an actual goal in practice and therefore seeks to generate new insights able to help shape applications of qualitative evidence to practice.[13] The data were gathered in spring 2018 with a semi-structured, one-to-one interview. The interviews lasted 30 minutes on average and were conducted at the women's homes on invitation. All women were informed about the study's purposes and signed an informed consent. The qualitative data were analysed using the method of content analysis.[14]

The study was performed as part of the European Union funded project Interreg V-A Italy-Slovenia 2014–2020 »Cross border network for migrant women: social integration, sexual and reproductive health – INTEGRA« and focused on various aspects of migrant women's lives. Within this project, the data collected was analysed from different perspectives and the findings in this book chapter are presenting one of this perspective. The funding source had no role in the: study design; collection, analysis and interpretation of data; writing of the manuscript; and decision to submit the manuscript for publication. The study was approved by the National Medical Ethics Committee (26. 10. 2017; No. 0120–544/2017/7).

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[12] Geri Lobiondo-Wood, Judith Haber: Nursing research: Methods and critical appraisal for evidence-based practice. 9th Edition. St. Louis, Missouri 2018.

[13] Janet Houser: The nursing research: reading, using, and creating evidence. 4th Edition. Burlington, Massachusetts 2018.

[14] Denise F. Polit, Cheryl Tatano Beck: Essentials of Nursing Research: Appraising Evidence for Nursing Practice. 9th Edition. Philadelphia 2017.

3. Findings

3.1 *Quantitative study findings*

The convenience sample included 52 migrant women. The participants' average age was 32.46 years (SD=8.06). Most participants (n=32; 61.5 %) had immigrated to Slovenia between 2014 and 2018. The average duration of their stay in Slovenia was 4.16 years (SD=7.25). Most of the migrant women included in the study come from the former republics of Yugoslavia (n=36; 69.2 %) or Russia (n=11; 21.2 %) and are members of the Orthodox Church (n=26; 50 %) or Islam (n=19; 36.5 %). With regard to their current employment status in Slovenia, 28 respondents (53.8 %) said they were unemployed or running a household and being at home; 24 (46.1 %) said they had a job. The majority of migrant women (n=44; 84.6 %) had completed at least upper secondary education or more. The main reason for moving to Slovenia was the desire to join a family member already living in Slovenia (n=29; 55.8 %). A similar proportion indicated marriage (n=10; 19.2 %) or work (n=11; 21.2 %). Participants were also asked whether they spoke the Slovenian language. More than 50 % do not speak Slovenian or speak it only a little.

The respondents named cardiovascular diseases such as arterial hypertension, acute myocardial infarction, angina pectoris, etc. (n=33) and diabetes (n=15) as the most common family diseases. Other family diseases cited by migrant women were diseases of the thyroid gland (n=7), liver disease (n=6), stroke (n=4) and cancer (n=4). Since having arrived in Slovenia, the health status of the majority of respondents (n=38) had not changed, although seven participants stated their health status had improved and four that the number of diseases had decreased. They most frequently sought help in a health facility for gynaecological problems (n=20), fever/infectious diseases (n=12) and injuries (n=10). Fifteen respondents (28.8 %) had experienced one or more abortions in the past. The latter mostly come from less developed republics of former Yugoslavia such as Kosovo (n=3), Bosnia and Herzegovina (n=3) and North Macedonia (n=4), as well as from Russia (n=3).

The participants were asked whether they had encountered any difficulties in society by virtue of belonging to a different ethnic group. Eleven respondents (21.1 %) answered this open question in the affirmative, with most mentioning communication problems due to their poor language skills (n=6) and, as a result, difficulties in integrating into everyday social life (e.g. socialising with neighbours). However, three respondents reported problems with finding work and two stressed they had encountered disrespectful behaviour in administrative offices.

Most respondents (n=51) stated they had not been subjected to any form of discrimination or violence in a healthcare institution; only one indicated she encountered less tolerance towards those who did not speak Slovenian properly. The biggest obstacle when in contact with a healthcare provider was the »language barrier« (n=32), but they also noted the »time constraints when dealing with foreigners« and »lack of knowledge of other cultures«. A large share of respondents (n=39.75 %) believed that interpreters/translators would be a possible solution for bridging communication problems in clinical settings. Another suggestion for improving communication between healthcare professionals/institutions and patients from other countries is to provide more healthcare professionals who either speak other languages or even come from other countries/cultures, as well as leaflets, brochures and instructions for foreign patients in different languages.

3.2 Qualitative study findings

The purposive sample included five women. The average age of the respondents was 34.6 years. Their education level was relatively low: three had completed elementary school, one vocational and one secondary school. Three women were nationals from North Macedonia, one migrated from Bosnia and Herzegovina, and one from Kosovo. Two of the respondents migrated to Slovenia because of marriage and three to re-join their husband who was a working migrant in Slovenia. Three women had two children and two women three. Their average age upon their first child was 18.6 years. All of the respondents included in the qualitative study had lived in Slovenia for over 10 years; three in the rural and two in urban parts. All of the women declared themselves to be Muslim.

The results of the content analysis, which was focused on »social diversity«, »access to healthcare« and »minority groups«, yielded two themes: (1) ensuring respectful care; and (2) culture affects access to healthcare.

The first theme of »respectful care« represents the respondents' perception that they had received appropriate care and were satisfied with the understanding shown by most of the healthcare professionals they had encountered. Besides pointing out the qualities of the health system in Slovenia compared to their home country, other aspects were also put in the forefront:

> »I'm very satisfied with the system here. When you get your turn, you receive care that you need. You always get your answers and things are explained to you.«

> »The health system is ›free‹ and this means a greater chance of health for you.«

One respondent who takes care of her two children, now both adults with intellectual disabilities, described her experience with the health system upon arriving in Slovenia. She described the understanding displayed by healthcare professionals, also informing her of her rights and access to health and social security possibilities for her family and herself.

> »There was that doctor, I cannot remember her name. She informed me so much about the things (diapers, wheelchair, hospital bed) I need for my two children and how to get them. This really improved my children's quality of life. […] When you arrive and you are new here, you do not know how to get things or access the health system. I'm perfectly aware that my children would have a different quality of life in Macedonia than here (Slovenia).«

She also described the role of the community nurse upon arriving in Slovenia, who not only assisted with accessing the health system or »bringing the health system to them«, but also helped them become more included in the community.

> »At the beginning, the children had nothing. They were at home. But then the community nurse came to us because she found out that we have two children with intellectual disabilities and asked me if I would accept her help. I answered that I would do so gladly. She suggested that it wouldn't be good that the children are at home all the time and that they need to be included in different development programmes in specialised institutions. And so both of them did. This helped them both a lot. She draws, reads, uses a mobile.«

The second theme »culture affects access to healthcare« is even more revealing. It emphasises the need for healthcare professionals to develop cultural competences and to empower them with cultural knowledge and skills, and for developing strategies to tackle cultural issues that limit access to healthcare due to patriarchy and gender issues. All of the women described how the gender of a healthcare professional is an important factor for accessing the health system, especially when the reasons involve gynaecology or obstetrics.

> »The gender of a practitioner is important. If you really need to see a doctor, you go to a male doctor if there is no other choice.«

> »Gender is an important factor. When I first arrived, I had a male doctor and I was so embarrassed, because of the exam. Afterwards, I found a female doctor, because in our culture a male doctor cannot touch you. I feel better with this doctor.«

One woman described an »offensive« experience, even though her own perception of it was different:

> »I had an older doctor. He was around 70 years. […] Two years ago, I had the feeling that something wasn't right here (showing her breasts) and I didn't want to go to the doctors. It was hard but finally I went. He mentioned to me that he sees that I'm embarrassed but that he is just doing his work. Then he said to take my shirt off. Then also my undershirt. At the end, he said he has to undress me like an onion (laughs). […] After this experience, my son changed the doctor and chose a female doctor.«

On that note, access to healthcare seems to be affected even before a woman enters the healthcare arena. Culturally-rooted gender issues and strong patriarchy, even if at first glance they do not seem very present, still shape women's access to healthcare. Each of the respondents confessed that they turn to a husband or another family member (most often mother-in-law) before going to see a doctor: »First I turn to a family member, then I go to the doctor.«

This was noticeable in another interview topic where one woman stated:

> »Concerning men as the authority in the family […] it is a bit strict. Well, not that strict, but it is polite to notify your husband before taking on a survey or doing an interview. A woman has to ask her husband, but it is her choice whether to participate or not.«

It may be concluded that the same principal applies when health issues emerge and women need medical assistance. In this context, the husband's presence during the examination is described in two cases that, despite being ethically questionable and causing a great dilemma for healthcare professionals in delivering care, is also a matter to be considered in terms of health system access. Refusing a husband might mean negative health outcomes for the woman or unwilling exclusion from the health system, e. g. cancer screening.

4. Discussion

The study shows the respondent migrant women had not often experienced any form of discrimination or violence in the health system. Moreover, they found the care provided to be adequate, pointing out the high quality of the healthcare system in Slovenia. The main difficulty they encountered in the clinical environment when in contact with healthcare staff was the language barrier. Therefore, introducing interpreters/translators could be a possible way to overcome the communication problems. However, the content analysis also revealed the need for healthcare professionals to develop additional cultural knowledge and skills.

In the 1990s, Slovenia was confronted with a major wave of migration due to the war in the Balkan region. At that time, refugees mainly from Bosnia and Herzegovina and Kosovo applied for asylum. Although up until recently Slovenia was mostly not the final destination for those coming to Europe from other continents for various reasons, the situation has changed somewhat in the last few years. In fact over the past decade, Slovenia, like other EU member states, has been under pressure due to the migration flows resulting from the conflicts in the Middle East and Africa.[15] This growing cultural diversity means that not only society but also the healthcare system is facing increasing challenges. The migrant population often has different habits, traditions and healthcare needs and therefore requires a different approach to medical treatment. Some studies suggest that migrants face various problems in the healthcare system in Slovenia, among which language barriers and healthcare professionals' lacking intercultural skills are the biggest problems.[16]

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[15] Blaž Lenarčič, Mateja Sedmak: Reproductive Health of Migrant Women in Slovenia: State of the Art. In: Sabina Ličen, Igor Karnjuš, Mirko Prosen (Eds.): Women, Migrations and Health: Ensuring Transcultural Healthcare. Koper 2019, pp. 35–57.

[16] Uršula Čebron Lipovec: »Ko nujno postane nenujno« Raziskovanje zdravstvenih

Language barriers make it difficult for women to find adequate care and understand health information.[17] Successful communication between migrants and healthcare professionals is essential and significantly impacts outcomes and health service delivery. Schmidt et al.[18] found that language barriers increase migrant women's insecurity and fear of using healthcare services and thus limit their access to healthcare facilities. This can delay or even prevent a visit to a specialist and lead to numerous misunderstandings or even traumatic experiences in the medical environment. Healthcare facilities in Slovenia are still reacting slowly to the presence of an ever more diverse population. In fact, the Slovenian health system does not have effective systemic solutions in place to overcome the language barrier in the clinical environment.[19] From a linguistic point of view, the Slovenian healthcare system may be characterised for its pronounced monolingualism. Indeed, interpreters/translators are not systematically regulated in the healthcare system in Slovenia. Moreover, brochures, instructions or various forms, e. g. informed consent, referrals to specialist medical examinations, in different languages other than Slovenian are rarely found. When migrant women do not speak Slovenian, their husband, relative or friend from the ethnic community is often involved in resolving the communication barriers with the health worker.[20] Although these ad hoc interpreters are often the sole solution available in the current situation, they might interpret inaccurately, omit or add information and thus contribute to many errors and misunderstandings in the clinical environment or fail to respect the confidentiality of data.[21] Policymakers are not the only

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vidikov migracije v Sloveniji [»When Urgent Becomes Non-Urgent«: Researching Health Aspects of Migration in Slovenia]. In: Glasnik Slovenskega etnološkega društva 57 (2017), pp. 54–64; Zorana Medarič, Mateja Sedmak: When Language and Culture Interfere: Sexual and Reproductive Health of Migrant Women in the Coastal Region of Slovenia. In: Ličen, Karnjuš, Prosen (Eds.):Women, Migrations and Health (Note 5), pp. 155–171.

[17] Ikhilor, Kurth, Asefaw, Pehlke-Milde, Cignacco: Communication Barriers in Maternity (Note 7).

[18] Schmidt, Fargnoli, Epiney, Irion: Barriers to Reproductive (Note 1).

[19] Uršula Čebron Lipovec, Lea Bombač, Nike Kocijančič Pokorn, Miha Lučovnik: Monoligual Health? Linguistic Barriers in Slovene Healthcare Experienced by Migrant/Refugee Women. In: Ličen, Karnjuš, Prosen (Eds.): Women, Migrations and Health (Note 5), pp. 139–153.

[20] Medarič, Sedmak: When Language and Culture Interfere (Note 6).

[21] Phyllis Butow, Elizabeth Lobb, Michael Jefford, David Goldstein, Maurice Eisen-

ones who should address the language barrier. At the operational level, health institutions should also more carefully address the problem by reviewing current practices and translating some health promotion/health education materials into different languages according to the actual demographic structure of migrants in the country. In this context, few projects have been carried out in Slovenia to translate some health materials into various languages, e.g. Albanian, Arabic, Russian, Turkish etc., and these are mainly disseminated through websites.[22]

Almost all study participants reported that they did not feel discriminated against by healthcare professionals; they also emphasised that they found the health system in Slovenia to be good. However, the results of the qualitative part of the study reveal a need to develop strategies to address the cultural problems that are hindering migrant women's access to health services as a result of patriarchy and gender issues. Culturally defined gender roles in conjunction with patriarchal values can have an impact on a woman's health.[23] Healthcare professionals must strive to provide culturally appropriate or congruent care, for which cross-cultural competencies are essential. The concept of intercultural competences underlines the importance of taking into account the linguistic, cultural and religious specificities of migrants who are treated in the health system.[24] Yet, recent studies show that many women still have negative experiences in the clinical setting due to the inadequate cultural competence of healthcare providers.[25] Indeed, some prejudices and stereotypes still exist in the

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bruch, Afaf Girgis, Madeleine King, Ming Sze, Lynley Aldridge, Penelope Schofield: A bridge between cultures: interpreters' perspectives of consultations with migrant oncology patients. In: Supportive Care in Cancer 20 (2012), pp. 235–244.

[22] Čebron Lipovec, Bombač, Kocijančič Pokorn, Lučovnik: Monoligual Health (Note 9).

[23] Christine Metusela, Jane Ussher, Janette Perz, Alexandra Hawkey, Marina Morrow, Renu Narchal, Jane Estoesta, Melissa Monteiro: In My Culture, We Don't Know Anything About That: Sexual and Reproductive Health of Migrant and Refugee Women. In: International Journal of Behavioral Medicine 24 (2017), pp. 836–845.

[24] Medarič, Sedmak: When Language and Culture Interfere (Note 6).

[25] Medarič, Sedmak: When Language and Culture Interfere (Note 6); Jana Sami, Katharina C. Quack Lötscher, Isabelle Eperon, L. Gonik, B. Martinez de Tejada, M. Epiney, Nicole C. Schmidt: Giving Birth in Switzerland: A Qualitative Study Exploring Migrant Women's Experiences during Pregnancy and Childbirth in Geneva and Zurich Using Focus Groups. In: BMC Reproductive Health 16 (2019), https://doi.org/10.1186/s12978-019-0771-0.

healthcare environment. In the past, no specific training was given in either formal studies or professional careers to prepare healthcare professionals for work in a culturally and ethnically diverse healthcare environment.[26] In the light of the demographic change and growing cultural diversity seen in the EU, healthcare professionals are becoming ever more aware of the need to acquire the necessary knowledge and skills in cultural competence because culturally competent care ensures patient satisfaction and thus leads to better health outcomes for a culturally diverse population.[27] In Slovenia, certain recent project-based initiatives have tried to fill this gap, e. g. by organising training courses on the cultural competence of healthcare professionals.[28] Educational institutions that train healthcare professionals are also becoming increasingly cognisant of the need to include transcultural content in their formal curricula at all levels of study.[29]

Several limitations of this study should be considered. In the quantitative part, we used a relatively small convenience sample. In addition, the quantitative and qualitative parts only included migrant women treated in a single regional maternity hospital in Slovenia. Caution should therefore be exercised when generalising the results of the study. Moreover, in qualitative research both the data and the conceptualised results are vulnerable to subjectivity. However, the mixed methods approach allows for more in-depth analysis with the possibility of combining the evidence in different ways, as dictated by the purpose of the study and the subject matter.[30] Most of the migrant women included in our study had a stable socio-economic background. Future studies should include newly arrived women with irregular status and different backgrounds, e. g. refugees, given that

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[26] Čebron Lipovec, Bombač, Kocijančič Pokorn, Lučovnik: Monoligual Health (Note 9).

[27] Ruth W. Gallagher, Joshua R. Polanin: A Meta-Analysis of Educational Interventions Designed to Enhance Cultural Competence in Professional Nurses and Nursing Students. In: Nurse Education Today 35 (2015), pp. 333–340.

[28] Čebron Lipovec, Bombač, Kocijančič Pokorn, Lučovnik: Monoligual Health (Note 9).

[29] Mirko Prosen: Developing Cross-Cultural Competences. In: Obzornik Zdravstvene Nege 52 (2018), pp. 76–80.

[30] Rashmita S. Mistry, Elizabeth S. White, Kirby A. Chow, Katherine M. Griffin, Lindsey Nenadal: A Mixed Methods Approach to Equity and Justice Research: Insights from Research on Children's Reasoning About Economic Inequality. In: Advances in Child Developmeđnt and Behavior 50 (2016), pp. 209–236.

experiences in this group with the healthcare system and healthcare professionals may vary.

5. Conclusion

Healthcare professionals have an important role to play in recognising the health inequalities and different needs of migrant women arising from their cultural and religious background. However, healthcare professionals also have an obligation to prevent and fight health inequalities, and to strive to ensure access to high-quality, safe, integrated, effective and women-centred healthcare. In the study, migrant women emphasised that language barriers and gender issues, particularly in relation to the healthcare provider, largely influence the quality of their medical treatment in everyday clinical practice. This finding underlines the need to adopt a socio-ecological approach at all levels of healthcare in order to improve the quality of care provided and avoid exclusion. Furthemore, given the relatively rapid changes in society, it is crucial that both the systemic and the operational levels of healthcare be adapted to the currently expressed needs of patients entering the health system. It is clear that the problem of health inequalities needs to be addressed in the context of health policy, which must be more responsive to the needs of migrants in general or other minority groups who have access to the health system. In addition, the lack of appropriate guidelines for clinicians and solutions to address the problems that typically cause health inequalities is evident.

In the future, we need to focus on improving research to better understand the phenomena of social integration and social equity within the health system, making health and social services more gender-sensitive, raising self-awareness and finding other ways to stimulate the development of cultural competences. The latter gives healthcare professionals a sense of self-empowerment, provides patients with a sense of equality and healthcare organisations a confirmation of the level of quality of care provided. Ultimately, they are also a reflection of social values and societal attitude towards those who must not remain invisible.

Alenka Kraigher, Nuška Čakš Jager

Occupational risks and protection from infectious diseases in contact with migrants and refugees

Abstract

Background: The health systems should protect the health of migrants, residents and health care workers at the same time. Avoiding crowding, ensuring sanitation and hygienic conditions, screening, health education and promotion, immunization, best practices and other measures are essential for communicable diseases control.

Methods: Review of literature, WHO and ECDC documents, the survey conducted among the five European countries (CARE project) and available national and international guidelines.

Results: The findings of this paper stress opportunities for increasing capabilities of healthcare systems, which can lead to improvement of the health and well-being of migrants, refugees and individuals from host communities, including health workers. On one hand the results show instances of challenges, on the other hand, examples of very good synergies between government, civil society and the public sector are presented.

Conclusions: In the European Region the risk of communicable diseases transmission from migrants to the host population was very low. Exchange of knowledge and training for staff involved in migrants' health care and application of preventive measures including personal protection and vaccination may contribute to better occupational and public health safety.

1. Introduction

For centuries, population movements have been one of the most important challenges and defining phenomena for the affected societies and migrating individuals. There are multiple reasons for migrations: violence, conflicts, natural disasters and human rights violations, which cause people to leave their homes. Moreover, lack of employment and subsequent poverty and hunger, is also a reason for the international migration of people. Migrant workers seeking employment make up a large proportion of international migrants worldwide. At least 100 million people have been forced to flee their homes and seek refuge either within or outside their country's borders in the last 10 years. Forced displacement and statelessness have been high on the international agenda in recent years and have continued to make dramatic headlines in all parts of the world. The influx of refugees and migrants into European Region since 2015 has occurred in a series of repeated occurrences. Large groups of refugees and migrants – ranging from tens to hundreds of thousands – move often simultaneously in different areas, and such movements increase during the summer. Several various factors, such as the social determinants of health, the risks and exposures in the origin, transit, and destination environments interact with individual biological and social factors and affect various health outcomes for refugees and migrants. »Refugees and migrants with pre-existing conditions or ones that they were unaware of (e. g. cardiovascular diseases, diabetes, pregnancy or malignancies) might not have had access to medical attention or treatment before or during their travel and arrive needing treatment.«[1]

The recent migration to Europe differs from previous migration occurrences. Above all visible are greater heterogeneity of arriving migrants and refugees and differences in their individual profile and motivation for movement, with more women and educated people choosing to cross the Mediterranean Sea.[2] Furthermore, observable is increased presence of vulnerable populations, for example unaccompanied minors more often migrating than in the past.[3]

These characteristics: the sheer number of immigrants, the increased presence of vulnerable groups, the heterogeneity of the arriving population and the growing anti-immigrant sentiment across Europe are putting immense pressure on protection, healthcare, legislative and other systems in both transit and destination countries, which must manage to work together and coordinate their actions.[4] Migrants and refugees are not a homogeneous group, and care sys-

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[1] World Health Organization: Report on the health of refugees and migrants in the WHO European region. Geneva 2018, pp. 1–114.

[2] Hassène Kassar, Paul Dourgnon: The big crossing: illegal boat migrants in the Mediterranean. In: European Journal of Public Health 24 Suppl. 1 (2014), pp. 11–15.

[3] The Organisation for Economic Co-operation and Development: Is this humanitarian migration crisis different? In: Migration Policy Debates 7 (2015) pp. 1–15.

[4] Philipa Mladovsky, David Ingleby, Bernd Rechel: Good practices in migrant health: The European experience. In: Clinical Medicine 12 (2012), pp. 248–252.

tems must respond to their diverse needs. The health systems should adequately contribute to protect the health of the resident population and health care workers at the same time. Systems for newly arrived migrants and refugees should address their needs in order to assure health assessments; adequate shelter to avoid crowding and ensuring good sanitation and hygienic conditions; screening for communicable diseases; health education and health promotion, immunization and other measures.

2. Methods

To describe the health care workers' safety due to migrants and refugees care in terms of integrated public health plans and actions we reviewed peer-reviewed and grey literature, WHO and ECDC documents addressing the issue of prevention and control of communicable diseases among migrants arriving in the EU Member States, the survey conducted among the five European countries involved in the CARE project and a review of available national and international guidelines on this issue. This paper uses the terms migrants and refugees, who are entitled to the same universal human rights and fundamental freedoms as all human people, which must always be respected, protected and fulfilled.

3. Results

Health and healthcare for migrants stood in the focus of multiple international consultations. In 2010, Health of Migrants: The Way Forward was created as a framework for action to help advance resolution of the World Health Organization and the World Health Assembly No. 61.17. This framework identified four key areas for action: the monitoring of migrant health through the collection of standardized and comparable data and best practices; the adoption of international policy and legal frameworks to ensure national health policies that promote equal access to health services and social security for all migrants; the creation of health systems that are responsive to the needs of migrants, financially sustainable, culturally sensitive, linguistically appropriate and delivered by professionals who are aware of the health challenges associated with migration; and the establishment of intersectional partnerships and frameworks for dialog and collaboration across sectors and regions for global and regional consultative processes.[5]

WHO European Region is characterized by fundamental differences in health care systems of particular countries.[6] These differences influence the way health care is organized, financed and regulated for the general population; they also impact particular national health policies for refugees and migrants. Among these differences the fundamental variability is visible in defining access requirements to health services. Furthermore, they influence the implementation of international regional policies, recommendations and guidelines. As the common baseline, recommended is provision of emergency and urgent care to all refugees and migrants at the European Region, regardless of the legal status of the person in question. In order to support the European Region in designing a common framework for advancement of refugee and migrant health, the WHO has developed a comprehensive plan of action, which is based on high-quality evidence and intersectional operation. This plan of action has been developed to focus on and interconnect interests of various actors: international partner organizations, Member States and other relevant stakeholders, as well as refugees and migrants themselves.[7]

One of the central priorities of this plan lies in the area of improvement of social protection for refugees and migrants. To achieve this goal and to ensure universal health coverage and social protection, indispensable is development of sustainable financing mechanisms, both at the national and international levels.[8]

In the context of WHO European Region, other international instruments and agreements have defined the fundamental rights of refugees and migrants and their access to health care. In countries where the constitution does not explicitly provide for these rights, numerous other protocols, agreements and related guidelines have been accepted that support refugee and migrant health.

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[5] World Health Organization: Health of migrants: the way forward: report of a global consultation, Madrid, Spain, 3–5 March 2010. https://apps.who.int/iris/handle/10665/44336 (accessed 26.1.2021).

[6] World Health Organization: Report on the health of refugees and migrants (Note 1).

[7] World Health Organization: Report on the health of refugees and migrants (Note 1)

[8] World Health Organization: Report on the health of refugees and migrants (Note 1)

3.1 Utilization of care services for refugees and migrants in the WHO European Region

In its »Report on the health of refugees and migrants in the WHO European Region« the World Health Organization reported on the implementation of health care services for migrants, stating that:

> Utilization of primary care services by refugees and migrant might be affected by the organization of the health system and whether payments are required for access. Provision of ethical and effective screening and health care for migrants at borders is an important step towards ensuring the health needs of refugees and migrants moving on into host communities.[9]

Furthermore, this Report presents conditions that affect utilization of health care services and which encompass several factors, from the availability of health care resources in particular countries to health care conditions of the arriving people:

> The speed and conditions with which these mobile populations arrived, and the number of people involved, created challenges for the countries receiving them. Refugees and migrants with pre-existing conditions or ones that they were unaware of (e.g. cardiovascular diseases, diabetes, pregnancy or malignancies) might not have had access to medical attention or treatment before or during their travel and arrive needing treatment. Apart from complications arising from lack of care, common infections acquired during displacement and migration and lack of nutrition can worsen these conditions. A commonly encountered problem relates to the integration of general medical services, psychosocial services and protection. Vulnerable or traumatized individuals (e.g. victims of trafficking and gender-based violence, victims of torture and trauma, and unaccompanied or orphaned minors) often have both physical and mental disorders.[10]

3.2 Collaboration and multisector partnerships

Some European countries have produced several cases of excellent collaboration between different stakeholders due to integrated public health plans and policies for incoming migrant and refugee populations. Some countries have tried to find efficient ways to design and

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[9] World Health Organization: Report on the health of refugees and migrants (Note 1), p. X.

[10] World Health Organization: Report on the health of refugees and migrants (Note 1), p. XI.

deliver health services to migrants and refugees. »Realization of integrated people-centred health services depend on health system inputs, including the availability, accessibility and quality of health workers and the services they provide.«[11] On the one hand, the challenges were lack of staff, not enough training in cultural competence for health and social care professionals, and lack of coordination between the participating organizations. On the other hand, there were very good synergies that developed between government, civil society and the public sector. The results showed the possibilities to improve the effectiveness of health care in a way that ensures the health and well-being of both migrants, refugees and host communities, including health workers.[12]

3.3 *Infectious diseases risk among migrants in the European Union/European Economic Area (EU/EEA)*

Although migrant groups, including children, entering the EU/EEA, are at the similar degree of risk of contracting infectious diseases as other population groups in the host countries, there are several additional risk factors that could affect them. These include the absence or inadequacy of healthcare in the country of origin, exposure to infections and lack of care in the transit countries through which they travelled, and poor living conditions in the destination country. Evidence suggests that the risk of transmission of communicable diseases from refugee and migrant populations to host populations in the WHO European Region is low.[13] Such communicable diseases include tuberculosis, which may be prevalent in the migrants' countries of origin. Similarly, infections with hepatitis B and C viruses may occur in migrant populations from countries in which these diseases are

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[11] World Health Organization: Framework on integrated, people-centred health services. In: Report by the Secretariat for the Sixty-ninth World Health Assembly. Provisional agenda item 16.1, A69/39, 15 April 2016, Geneva 2016, p. 4.

[12] World Health Organization: Framework on integrated, people-centred health services, pp. 1–12 (Note 7).

[13] Rosalia Marrone, Giovanni Baglio, Giusy Bruscino, Gianfranco Costanzo, Andrea Cavani, Concetta Mirisola: Prevalence of latent tuberculosis infection, hepatitis B, hepatitis C, and syphilis among newly arrived unaccompanied minors living in reception centers in Rome. In: International Journal of Infectious Diseases 15 (2020), pp. 126–130.

endemic; however, the number of individuals with these infections varies in different migrant populations across Europe.[14] In case of HIV infections visible is that a significant proportion of HIV-positive refugees and migrants became infected after their arrival in Europe. Therefore, the HIV infections are more likely to be diagnosed not directly after the arrival, but in a later period.[15] Tropical and parasitic infections not normally found in Europe are observable in migrant populations coming from territories with high endemicity of such infections. The risk for EU/EEA countries of experiencing outbreaks of infectious diseases because of the current influx of migrant population is extremely low. Although there is a low, or in some cases very low, likelihood of occurrence among migrants of the specific infectious disease risks they should be considered in order to ensure that they are recognized and treated in a timely manner, or prevented by immunisation when indicated they do not represent a significant risk for EU/EEA populations.

Overcrowding in refugee facilities can favour outbreaks of meningococcal disease. Especially sharing dormitories, poor hygiene, and limited access to medical care have been reported as contributing factors. Although meningococcal disease primarily affects children, it is still a leading cause of both meningitis and sepsis in adolescents, young adults and adults, especially in densely populated facilities that harbour newly-incoming migrants. Moreover, overcrowding of refugee camps can lead to heightened transmission of other diseases, e. g. measles, varicella and influenza.

3.4 Good practices in healthcare for migrants

One of the important initiatives regarding provision of healthcare for migrants and refugees constitutes project CARE (Common Approach for Refugees and other migrants' health). Within the framework of

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[14] Marrone, Baglio, Bruscino, Costanzo, Cavani, Mirisola: Prevalence of latent (Note 3).

[15] Gianluca Cuomo, Iacopo Franconi, Nicoletta Riva, Alesandro Bianchi, Margherita Digaetano, Antonella Santoro, Mauro Codeluppi, Andrea Bedini, Giovanni Guaraldi, Cristina Mussini: Migration and health: A retrospective study about the prevalence of HBV, HIV, HCV, tuberculosis and syphilis infections amongst newly arrived migrants screened at the Infectious Diseases Unit of Modena, Italy. In: Journal of Infection and Public Health 12 (2019), pp. 200–204.

this project, the general objective is to promote and maintain the health of migrants in the European Union member states, especially in countries which are commonly a popular destination of migration and which are because of it under strong migratory pressure. In the report presented is an overview of the current serious situation regarding migration and health. Moreover, shown are the differences between three participating countries – Greece, Italy and Slovenia – with the focus on the role of civil society organizations in these countries.[16]

The report focuses on examples of good practice proposals from non-governmental organizations in Greece and Italy, which worked together with public authorities and other administrative institutions in these countries on preparation of health determination and prevention measures for migrating people. Several recommendations are presented in this report with regard to strategic planning of Public Health measures in provision of healthcare to migrants and refugees. These recommendations are proposed for various levels – from international, European level to the national level and focus on the role and responsibilities of civil society organizations. In examining in detail the integrated public health plans and policies implemented by Greece, Italy and Slovenia for incoming migrant and refugee populations in 2015–2016, several cases emerged of excellent collaboration between different stakeholders.[17]

Visible was lack of coordination in between particular services established for help for migrants and refugees; however, at the same time, observable were very good synergies between various actors from the governmental, civil society and public sectors. In accordance with this observation, opportunities for improving the effectiveness of health care may lay in coordination of actions on various levels. In

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[16] Maria Psoinos, Christina Karamanidou, Elisabeth Ioannidis, Dimitris Papamichail, George Koulierakis, Maja Sočan, Silvia Declich, Sara Albiani, Giovanna Tizzi, Giulia Borgioli, Maria José Caldés Pinilla, Paolo Pezzati: Recommendations for strategic Public Health planning regarding migrant and refugee populations and the role of civil society organisations (2017). https://www.researchgate.net/publication/319932418_Recommendations_for_strategic_Public_Health_planning_regarding_migrant_and_refugee_populations_and_the_role_of_civil_society_organisations (accessed 26.1.2021).

[17] Psoinos, Karamanidou, Ioannidis et al.: Recommendations for strategic Public Health (Note 6).

this way, health and well-being of both migrants, refugees and host communities may be achieved.[18]

Other examples of similar best practices in provision of health care for migrant populations have been presented previously.[19] However, in this context, important is to note that specificity of the current socio-economic and political context in Europe, such as massive population influx, with heterogeneous profiles of migrating populations and their vulnerability makes it imperative to identify and implement examples of best practices from various countries and different situations. Especially with regard to increasingly hostile climate towards migrants and refugees in some destination countries, such action is an imperative.[20]

Although the number of migrants crossing Slovenian border in 2015 was more than a quarter of total population), the situation was handled quite well. This was partially due to good cooperation and coordination between National Institute of Public Health and different departments within Ministry of Interior (such as the police and military). Instructions and relevant necessary materials were handed to appropriate personnel, after assessing the situation accordingly. Furthermore, there was also good cooperation between NGOs and governmental departments. There were also quite a lot of volunteers from general population. Cooperation among many different countries, all involved and assisting with the migrant crisis in Slovenia – there were police, health care workers and volunteers coming from other countries.

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[18] Psoinos, Karamanidou, Ioannidis et al.: Recommendations for strategic Public Health (Note 6).

[19] Stefan Priebe, Sima Sandhu, Sónia Dias, Andrea Gaddini, Tim Greacen, Elisabeth Ioannidis, Ulrike Kluge, Allan Krasnik, Majda Lamkaddem, Vincent Lorant, Rosa Puigpinósi Riera, Attila Sarvary, Joaquim J. F. Soares, Mindaugas Stankunas, Christa Straßmayr, Kristian Wahlbeck, Marta Welbel, Marija Bogic: Good practice in health care for migrants: views and experiences of care professionals in 16 European countries. In: BMC Public Health 11 (2011), https://doi.org/10.1186/1471-2458-11-187.

[20] Psoinos, Karamanidou, Ioannidis et al.: Recommendations for strategic Public Health (Note 6).

4. Discussion

The utter number of migrating people, their vulnerability and growing diversity, and the increase in anti-immigration attitudes across Europe are undoubtedly putting immense pressure on the protection, health, legislative and other systems in both transit and destination countries, which must manage to work together and coordinate their actions.

Quality care for refugee and migrant populations cannot be managed by health systems alone. Addressing refugee and migrant health care also provides an opportunity to identify gaps in routine service delivery and financing arrangements for the host populations. Therefore, it can improve and strengthen universal health coverage. It is a focus of many existing WHO strategies and action plans. Health systems should be adequately prepared to assist migrants/refugees while protecting the health of professionals and resident populations. Evidence suggests that the risk of transmission of communicable diseases from migrant and refugee populations to host populations in the European Region is very low, although it is possible that refugees and migrants from countries with a high prevalence of tuberculosis, HIV, hepatitis B and C may arrive.[21] Tropical and parasitic infections not normally found in Europe may, however, in some cases be introduced through migration movements, especially through refugees, migrants and travellers originating from or visiting areas of higher endemicity.[22] Although the likelihood that the specific infectious disease risks will occur among migrants and refugees is very low, they should still be treated in a timely manner, or prevented by immunization when indicated. Continuous sharing and exchange of knowledge and training for staff involved in migrants and refugees health care and conscious application of preventive measures including personal protection and vaccination may contribute to better occupational and public health safety.[23]

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[21] Marrone, Baglio, Bruscino, Costanzo, Cavani, Mirisola: Prevalence of latent (Note 3).

[22] Joaquín Salas-Coronas, María Teresa Cabezas-Fernández, Ana Belén Lozano-Serrano, Manuel Jesús Soriano-Pérez, José Vázquez-Villegas, José Ángel Cuenca-Gómez: Newly Arrived African Migrants to Spain: Epidemiology and Burden of Disease. In: The American Journal of Tropical Medicine and Hygiene 98 (2018) pp. 319–325.

[23] Kevin Pottie, Alain D. Mayhew, Rachael L. Morton, Christina Greenaway, Elie A. Akl, Prinon Rahman, Dominik Zenner, Manish Pareek, Peter Tugwell, Vivian Welch,

It is of utmost importance to provide a basis for informed policymaking and countering myths regarding the migration through evidence-based research and information. One of such existing claims – namely that refugees and migrants are a source of communicable diseases in host countries – does not reflect reality. On contrary, evidence suggests that the risk of transmission of diseases through individuals migrating to Europe is very low.[24] Employees at the front lines of receiving and working with migrants may face an occupational risk of certain biological and chemical health hazards, such as having a direct contact with human secretions (e. g., blood, faeces, urine, saliva) or working continuously in polluted and/or odorous environments. Those working in long-term facilities may also face significant mental health hazards. The presence of certain occupational health hazards on one side and the demonstrated low level of appropriate knowledge on the health impact of assisting migrants on the other side have an unfavourable impact. Furthermore, results of study primarily focused on comparison of the awareness of the risks of employees who may have direct contact with migrants at different facilities indicate that there are considerable gaps in the training program for those working with migrants concerning the health-related aspects.[25]

Thus, well-designed, properly conducted educational programs and the incorporation of health aspects into undergraduate training for staff focusing on raising awareness about the health risks of international migration would be of crucial importance for public health. Several factors, such as low immunization coverage, adverse conditions during the migration and overcrowding of facilities for migrants in the reception countries may favour outbreak of diseases. Evidence suggests that such outbreaks can be prevented by vaccinations provided to the migrants. As explored through online survey on immu-

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Joerg Meerpohl, Pablo Alonso-Coello, Charles Hui, Beverley-Ann Biggs, Ana Requena-Méndez, Eric Agbata, Teymur Noori, Holger J. Schünemann: Prevention and assessment of infectious diseases among children and adult migrants arriving to the European Union/European Economic Association: a protocol for a suite of systematic reviews for public health and health systems. In: BMJ Open 7 (2017), https://doi.org/10.1136/bmjopen-2016-014608.

[24] Cuomo, Franconi, Riva, et al.: Migration and health (Note 5).

[25] Istvan Szilard, Zoltan Katz, Karoly Berenyi, Peter Csepregi, Andras Huszar, Arpad Barath, Erika Marek: Perception of Occupational Risks and Practices of Self-protection from Infectious Diseases Among Workers in Contact with International Migrants at Hungary's Border. In: Journal of Rural Medicine 9 (2014), pp. 59–73.

nization strategies targeting migrants, several countries, e. g. Croatia, Greece, Italy, Malta, Portugal and Slovenia offer all vaccinations included in their National Immunization Plan to migrant children and adolescents.[26]

5. Conclusion

Health of refugees and migrants may be determined by several aspects, ranging from specific health determinants in the country from which they migrate, as well as circumstances occurring during transit and at the host countries. Hazardous travel, detention, violence and exploitation occurring during migration, but also acculturation after the arrival to the destination country coupled with living and working conditions that are risky to health, and limited or conditional access to health care are only a few examples that show the necessity of specific approach towards this issue. In consequence, transit and destination countries need to develop appropriate strategies, including long-term policy measures and adapt their national healthcare systems to pressures caused by migration. Only through such strategies, the challenges faced by refugees and migrants in accessing health care can be addressed appropriately. Migrants arriving to the Europe are generally in good health. Traveling conditions might make some migrants more vulnerable to health threats, due to exposures before arriving to the EU combined with low vaccination coverage. For this reason, it is important for front line health care workers assessing the health of newly arrived migrants in point of entry, to be aware of the epidemiology of disease and vaccination status. Evidence suggests that there is a very low risk of transmission of communicable diseases from the migrant and refugee population to the host population in the European Region. Quality care for refugee and migrant groups cannot be addressed by health systems alone. Social determinants of health cut across sectors such as education, employment, social security and housing. The health systems should be adequately prepared to

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[26] Cristina Giambi, Martina Del Manso, Teresa Dalla Zuanna, Flavia Riccardo, Antonino Bella, Maria Grazia Caporali, Agoritsa Baka, Nuska Caks-Jager, Tanya Melillo, Ricardo Mexia, Goranka Petrovic, Silvia Declich, The CARE working group for the National Immunization Survey: National immunization strategies targeting migrants in six European countries. In: Vaccine 37 (2019), pp. 4610–4617.

provide aid to migrants/refugees while at the same time protecting the health of professionals and the resident population. Continuous sharing and exchange of knowledge and training for staff involved in migrants and refugees' health care and conscious application of preventive measures including personal protection and vaccination may contribute to better occupational and public health safety. Certainly, unforeseen events such as COVID-19 pandemic demonstrate how migrations forecasts can be influenced. The subsequent pandemic continues to have, an unprecedented global social and economic impact, which also affects asylum systems that slowed or stopped when countries closed borders or implementing strict border restrictions in response to COVID-19.

Nina Fritz

Healthcare of migrants at the Reception Centre Brežice

Abstract

Slovenia first faced the migrant crisis in 2015, after the conflict in Syria started, since the country presents an important transit point on the Balkan migrant route. Besides the socio-political issues, this also proved to be a serious public healthcare challenge. At first, migrants were entering Slovenia from neighbouring Croatia in the municipality of Brežice. To handle the first groups, a reception centre was initially set up at the Brežice police station and later on expanded to the area of the abandoned foundry, factory Beti and the Dobova railway station. Emergency medical care was also set up within the reception centre while those in need of extensive medical care were taken to the General Hospital Brežice. Slovenia was not prepared for the 2015 migrant wave. It turned out that during peacetime healthcare systems are not prepared for extreme events such as the mass migration in 2015. Nevertheless, the Slovenian public came together and quickly made the necessary preparations to welcome and attend to the migrants who were oftentimes in poor health. With the incredible engagement of everyone involved, both healthcare providers as well as volunteers, we were able to manage the situation.

1. Introduction

Migration or the displacement of people is a complex global phenomenon that countries all over the world are facing. According to the World Health Organization (WHO), 68 million people had to leave their homes due to violence and find shelter outside their native countries. Refugees, asylum seekers and migrants are vulnerable population groups. This rapid increase in human migration significantly affects public health and thus requires an appropriate response from the healthcare system. In accordance with the constitution of the WHO, every person has the right to enjoy the highest attainable standard of physical and mental health. To protect migrants and refugees, including their right to health, there are ratified international standards and human rights conventions. However, numerous refugees and migrants do not have access to medical services and health protection.[1]

In the autumn of 2015, a record number of migrants arrived in Greece. This also directly affected the Western Balkans migration route, as people who entered the European Union (EU) in Greece tried to make their way to Western Europe through the former Yugoslav republics. Throughout 2015, the region recorded 764,033 illegal border crossings of migrants, sixteen times more than in 2014. Most of them were Syrians, followed by Iraqis and Afghans.[2]

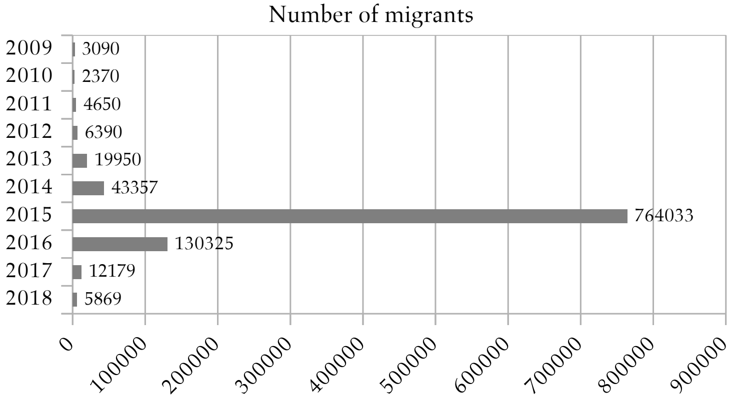

Figure 1: Illegal border crossings on the Western Balkans migrant route in numbers

Between September 2015 and March 2016, approximately 470,000 refugees and migrants from troubled parts of the world crossed the territory of Slovenia, resulting in a large-scale humanitarian disaster that required lots of coordination from numerous governmental and non-governmental organizations.

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[1] World Health Organisation: Refugee and migrant health: Draft Global Action Plan »Promoting the health of refugees and migrants« 2019–2023. https://www.who.int/migrants/GlobalActionPlan.pdf?ua=1 (accessed 18. 9. 2020).

[2] Frontex: Migratory Routes. https://frontex.europa.eu/along-eu-borders/migratory-routes/western-balkan-route/ (accessed 18. 9. 2020).

In cases of large-scale natural and other disasters we must quickly implement measures to prevent or reduce the number of casualties and other negative consequences, employing interdisciplinary collaboration of various protection and rescue services.

2. Methods

For this article, a descriptive research method was used, involving data gathering, critical review, evaluation, and analysis of domestic and foreign literature dealing with the issue of medical care of refugees and migrants. As for the operations at the reception centre Brežice, we contacted local healthcare organizations and the Ministry of Health, which provided us with various documents and reports on the activities of healthcare organizations during the migrant crisis in Slovenia in 2015 and 2016. While the reception centre was operational, it had to submit daily reports to the Ministry of Health on its activities. We analysed the obtained data and present it here in the form of tables and charts. So far there are no published studies on the migrant crises available in Slovenia.

3. Results

3.1. Terminology

Refugee is a person running from armed conflict or persecution. The position refugees find themselves in is often so dangerous and intolerable that they will cross national borders and seek safety in neighbouring countries. After being officially recognized as a »refugee«, they can get help from countries, the United Nations High Commissioner for Refugees (UNHCR) and other organizations. Refugees are entitled to this status because it is too dangerous for them to return home, which is why they need to seek shelter elsewhere. The 1951 Refugees Convention defines who is considered a refugee and defines their fundamental rights, which every country must uphold. The basic principle established by international law is that refugees may not be deported or returned to the surroundings where their life and freedom would be in danger. They must be allowed to live with dignity and in security in the country in which they have taken shelter, while at the same time a long-term solution must be found for them.[3]

Migrant is a person who migrates mostly to improve his/her quality of life by seeking work, not due to direct danger of persecution or death. In some cases, migrants migrate on account of education, family reunification or other reasons. Unlike refugees, who cannot return home, migrants do not face such obstacles. If they decide to return home, they will enjoy protection from their government.[4]

Reception-registration centres were set up due to increased illegal migrations at some locations along the border with Croatia. These were temporary, established in order to ensure the safety of people living near the border. The purpose of these centres was to process all persons that the police intercepts illegally crossing the border as close as possible to the border and point of return to Croatia. Migrants are supposed to be held at the reception-registration centres for a short time, 72 hours at the most, during which their movement is limited. During this time, foreigners were returned to the safe country, from which they illegally entered into Slovenia, or accommodated at the Centre for Foreigners or the Asylum Centre if they applied for international protection. The reception-registration centres were therefore temporary in nature, closed off and under constant police supervision. All transports to and from the centre were carried out by the police, thereby ensuring oversight over the migrants. Migrants were offered emergency medical assistance at the centres, children and unaccompanied minors were also taken care of.[5]

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[3] Adrian Edwards: UNHCR viewpoint: ›Refugee‹ or ›migrant‹ – Which is right? UNHCR, the UN Refugee Agency (11.7.2016). https://www.unhcr.org/news/latest/2016/7/55df0e556/unhcr-viewpoint-refugee-migrant-right.html (accessed 18.9.2020).

[4] Edwards: UNHCR viewpoint (Note 3).

[5] Government of the Republic of Slovenia: Pomoč beguncem, odziv Slovenije [Aid to refugees, Slovenia's response]. http://vlada.arhiv-spletisc.gov.si/pomoc_beguncem/odziv_slovenije/index.html (accessed 18.9.2020).

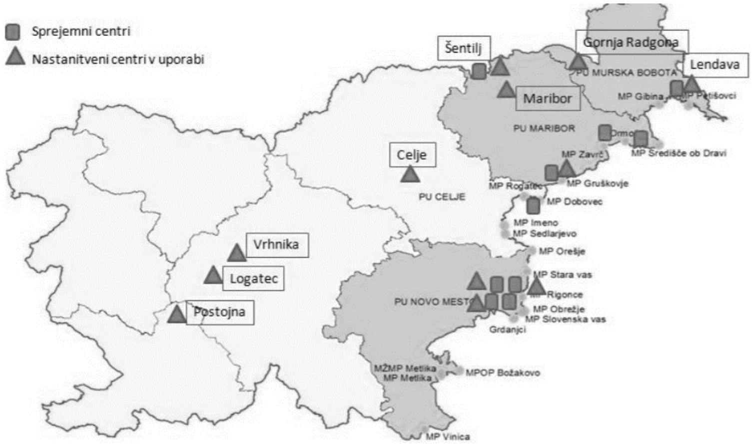

Figure 2: List and locations of reception and accommodation centres[6]

3.2. *Timeline of events at the reception centre Brežice*

3.2.1. First migrant wave

In Slovenia, we noticed the first increased number of migrants crossing into our territory in the middle of September 2015. The first wave of migrants crossed Slovenia between the 17th and 22nd of September 2015, when approximately 3,500 people passed through our territory. The border crossings with the Republic of Croatia in the municipality Brežice – Obrežje and Rigonce – were the main entry points for migrants. Slovenia was a transit country for the migrants, which is why they were taken care of, offered accommodation and processed in accordance with Slovenian and European law. Most migrants were issued a temporary permit to stay in the country, meaning they could

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[6] Government of the Republic of Slovenia: Seznanitev Vlade Republike Slovenije s poročilom o opravljenih aktivnostih ob drugem valu migracij na ozemlje Republike Slovenije v času od 15. 10. 2015 od 8. 12. 2015 s predlogi sklepov – novo gradivo št. 2 [Acquaintance of the Government of the Republic of Slovenia with the report on the activities carried out during the second wave of migration to the territory of the Republic of Slovenia in the period from 15. 10. 2015 to 8. 12. 2015, with proposals for resolutions – new material No. 2.]. (22. 12. 2015). http://vlada.arhiv-spletisc.gov.si/fileadmin/dokumenti/si/sklepi/seje_vlade_gradiva/VRS-migrant2-3_20_68.pdf (accessed 18. 9. 2020).

move freely around the country and had an open path to Austria at the same time.[7] During the first days, medical care was provided by the Brežice Medical Centre and its team for emergency medical assistance (NMP). However, they soon realized that they will no longer be able to ensure adequate treatment for their citizens due to the numerous interventions at the border crossings of Rigonce and Obrežje. On their own initiative and employing their own human resources, they activated an additional NMP team. And on the 18th of September 2015, an outpatient clinic was established by the medical centres Brežice and Krško on the premises of the Brežice police station, which also served as a migrant reception centre. On the 19th of September 2015, a coordination group for the integrated medical care of migrants in the Lower Sava region was established, and the group began to set up an additional emergency medical assistance system with outpatient services at the reception centre at the Brežice police station. A trailer for mass emergencies for the Dolenjska region was also activated. Healthcare institutions from the wider region participated in the activities – Health centres in Brežice, Krško, Sevnica, Novo mesto, Šmarje pri Jelšah and General Hospital Brežice. The work equipment at the clinic and in the field was brought from Health centres Brežice and Krško, medicine and sanitary preparations were provided by Health centres Brežice and Krško during the first days, and later some were also brought in from the national supply. On the 22nd of September 2015, the coordination group was dismantled, there was also no further need to organize additional medical teams at the reception centre at the Brežice police station, as the flow of migrants (temporarily) stopped.[8]

3.2.2. Second migrant wave

The second migrant wave began during the night of 16–17 October, after Hungary decided to close its border, and lasted until the 8th of

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[7] Mojca Pristavec Dogič, Marjana Križaj: Migrantska kriza – Primer Slovenije. Podatki [Migrant crisis – The case of Slovenia. Data]. Državni zbor, Raziskovalno-dokumentacijski center (30. 6. 2016). https://fotogalerija.dz-rs.si/datoteke/Publikacije/Zborniki_RN/2016/Migrantska_kriza_v_Sloveniji_-_primer_Slovenije.pdf (accessed 20. 9. 2020).

[8] Coordination Group for Integrated Medical Treatment of Migrants in the Lower Sava region: Report on the implementation of medical treatment measures and the establishment of an emergency medical assistance system for treating refugees in the Lower Sava region at the reception centre in Brežice and ensuring medical assistance at two border crossings. Rigonce, Obrežje 2015.

March 2016, when the decision to close the Western Balkan migration route was made. In only a few days, the number of migrants entering into Slovenia reached numbers significantly above the agreed-upon quotas. Once again, the inflow of migrant was largest in the municipality of Brežice, where besides the reception centre on the premises of the Brežice police station two additional reception centres were set up in a very short time in Dobova (Livarna located at a former foundry and one at the factory Beti). Every day between 8,000 and 9,000 migrants arrived, and occasionally even more than 10,000. The record was reached on the 21st of October 2015, when a little less than 13,000 migrants entered the territory of the Republic of Slovenia. The number of migrants at individual reception centres exceeded 2,000 several times, which is why security issues arose from migrants expressing their dissatisfaction with having to wait to undergo registration procedures implemented by the police. At the reception centre in Brežice, a serious incident occurred on account of this, namely a fire. Some migrants also caused disturbances at the reception centres, thereby compromising the safety of others. The situation improved after additional police officers and members of the Slovenian Armed Forces were sent to the locations. From the reception centres, migrants were transported with trains or buses to accommodation centres within the country (Vrhnika, Celje, Gronja Radgona and Šentilj), from where they were brought to the agreed-upon entry points at the border with Austria.

After the 4th of November 2015, the flow of migrants decreased slightly due to the sailors' strike in Greece. Approximately 6,000 to 7,000 migrants arrived every day, though towards the end of November the numbers began to drop to 2,000 to 3,000 per day. So it was mostly possible to hand over the migrants to the Austrian security authorities on the same day. With the coordinated efforts of all parties involved, the majority of migrants did not spend more than one day in Slovenia. The scope of the migrant situation required the deployment of additional workforce and resources, and the broader international community has also been called on for assistance.[9] During the second migrant wave, medical aid has been organized in a similar fashion as during the first wave. For the most part, the migrants ar-

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[9] Government of the Republic of Slovenia: Seznanitev Vlade Republike Slovenije s poročilom (Note 6).

rived at the border crossing at Rigonce in an organized manner and Slovenian authorities escorted them from there to one of the reception centres or transported them to accommodation centres.

Until the 30th of October 2015, the reception centre in Brežice had four sites where migrants received first aid. At the reception centre on the premises of the Brežice police station, two clinics offering emergency medical assistance were operational. On average, 4,000 people were accommodated there, and an independent dispatch centre was also established.

At the border crossing of Rigonce (green border), between 1,500 and 3,000 migrants awaited further processing. Here, interventions were mostly implemented in the field. Migrants in need of assistance were brought for examination to the clinic at the Brežice police station. Numerous field interventions were carried out along the route the migrants had to walk to get to the reception centres, especially on the embankment along the river Sava.

At the location Livarna in Dobova, a team of the Hungarian Caritas agency was active with its field clinic consisting of 4 doctors and 4 nurses. Slovenian teams offering emergency medical assistance implemented emergency transports when required. On average, between 3,000 and 5,000 migrants were accommodated there.

On the premises of the factories Beti in Dobova, between 1,500 and 3,000 migrants were accommodated on average. A clinic was set up at this location, with medical students also participating in its operation.

After the 30th of October 2015, only the site at Livarna Dobova remained open, where the Hungarian Caritas continued to carry out its activities (later replaced by a team from Slovakia), and the site at the railway station in Dobova, where domestic teams worked.

During the second wave, the following healthcare institutions participated in offering medical assistance to migrants in the region of the reception centre Brežice: Health Centres in Brežice, Krško, Sevnica, Novo mesto, Celje, Ljubljana, Slovenske Konjice, Ivančna Gorica, Trebnje, Črnomelj, Kočevje and Metlika, Pacient, Slovenian Armed Forces, paediatric residents, the Faculty of Medicine Ljubljana and Faculty of Medicine Maribor with support from their medical students, the Faculty of Health Sciences Ljubljana with support from their healthcare students, General Hospital Brežice, as the regional hospital, and the Slovenian Red Cross. International collaboration has also been established with the aforementioned Caritas, Doctors

Without Borders (MSF) and an emergency medical assistance team from Slovakia.[10]

After the 1st of December 2015, medical treatment of migrants at the reception centre Brežice has mostly been implemented by the international organization Women and Health Alliance (WAHA) and, if required, also with the participation of medical personnel of the Republic of Slovenia (teams for emergency medical assistance, hospital staff and volunteers from the healthcare sector).[11]

3.3. Statistics of treatments at the reception centre Brežice

3.3.1. First migrant wave

Statistical data on medical treatments have been kept as of the 18th of September 2015 onwards and are incomplete.

Date	**Number of people examined at the reception centre clinic**	**Number of field interventions**	**Number of people examined in the field**	**Total number of people examined**
18.9.2015	42	11 (NMP ZD Brežice)	16	58
19.9.2015	71	1 (NMP ZD Brežice) + 4 (from SC Brežice)	16	87
20.9.2015	29	6 (from SC Brežice)	6	35
21.9.2015	26	0	0	26
Total	168	22	38	206

Table 1: Number of medical treatments at the reception centre Brežice during the first migrant wave[12]

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[10] Coordination Group for Integrated Medical Treatment of Migrants in the Lower Sava region: Report of the coordination group for integrated medical treatment of migrants in SC Brežice for the 2nd wave of migrants from the 17th of October 2015 to the 3rd of November 2015. Rigonce, Obrežje 2015.

[11] Ministry of Health of the Republic of Slovenia: Report on the Ministry of Health's activities regarding the provision of medical care to migrants. Ljubljana 2016.

[12] Coordination Group: Report (Note 8).

It is assumed that we can add at least 100 unrecorded treatments to the total number of medical treatments. According to data from the Ministry of Health, six migrants have been transported to General Hospital Brežice during this time. The medical personnel mostly treated migrants suffering from dehydration, chest pain, urinary tract infections, upper respiratory tract infections, injuries (muscle pain, particularly in the lower limbs, blisters, ankle sprains) and fatigue. They also treated a couple of pregnant women.

3.3.2. Second migrant wave

All data published here is summarized according to sources of the Ministry of Health of the Republic of Slovenia.

3.3.2.1. Activities of Slovenian medical teams between the 18th of October 2015 and the 30th of November 2015

For the period between the 18th of October 2015 and the 4th of November 2015 we have relatively reliable statistical information, gathered by the coordination team. Within this time period, approximately 100,000 migrants entered Slovenian territory via the border crossing Rigonce. Slovenian medical teams provided medical assistance to 1,064 migrants, 663 of whom were adults and 402 children. The most common health problems among the migrants are presented in the table below.

Health problem	Number of migrants
Acute respiratory infection (ARI)	262
Abdominal pain, gastroenteritis	201
Injuries	63
Dehydration	59
Muscle and joint pain	57
Rash	50
Febrile state	42
Gynaecological problems	40
Hypothermia	32
Collapse	26
Urinary tract infection	21
Diabetes with complications	20

Headache	19
Eye problems	17
Problems of psychogenic origin	17
Toothache	16
Hypertension	12
Wound dressing	11
Allergy	7
Urgent surgical conditions	6
No diagnosis recorded	50

Table 2: Most common health problems of migrants between the 18th of October 2015 and the 4th of November 2015

We only have indicative information about the activities of the Hungarian Caritas agency for this time period, stating that they treated 631 migrants.

After the 4th of November 2015, when the flow of migrants somewhat decreased due to the sailors' strike in Greece, the number of medical treatments also decreased. For the month of November, the statistical data is insufficient. There is only data on the daily number of migrant examinations. The daily number of examinations ranged from 5 to 32 treatments per day.

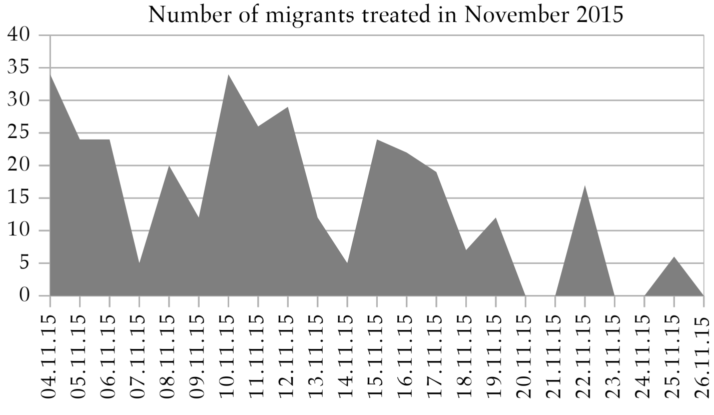

Figure 3: Number of migrants treated in November 2015

By the 16th of November 2015, 281 migrants had been treated at the General Hospital Brežice.

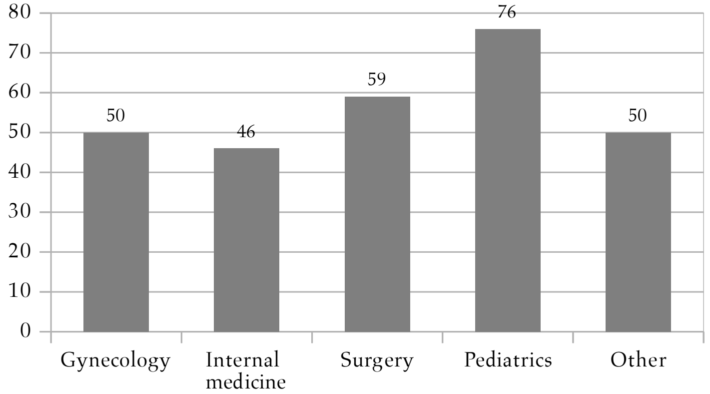

Figure 4: Number of migrants treated at individual departments of General Hospital Brežice

The most common health problems of migrants were abdominal pain, sprains, dehydration, hypothermia, hypoglycaemia, exhaustion, otitis media, intestinal infections, bleeding and pregnancy check-ups. On the 2nd of November 2015, one migrant was put on dialysis, and on the 3rd of November 2015, one migrant with suspected tuberculosis was transferred to the University Clinic Golnik.

We have no data on the treatment of migrants by the Hungarian Caritas for the period after the 4th of November 2015.

3.3.2.2. Period between the 1st of December 2015 and the 8th of March 2016

At the end of November 2015, the Ministry of Health set up a system of daily reporting on the number of treated migrants via a special application. For this period, we only have very imprecise data on the number of examined migrants and their medical problems. In this period, the majority of medical care was provided by foreign medical organizations, with the help of domestic emergency medical assistance teams.

Month	**Number of medical treatments**	**Number of medical treatments – children**	**Number of medical treatments – pregnant women**	**Births**
December 2015	2816	961	94	0
January 2016	2261	774	55	0
February 2016	1549	612	41	0
March 2016	170	66	6	0

Table 3: Number of medical treatments of migrants December 2015 – March 2016

Month	**Number of people taken to the hospital**	**Number of people taken to the hospital – children**	**Number of people taken to the hospital – pregnant women**	**Number of field interventions**
December 2015	51	19	1	40
January 2016	32	9	4	32
February 2016	12	1	2	12
March 2016	0	0	0	0

Table 4: Number of hospital treatments and interventions December 2015 – March 2016

Approximately 80 % of all problems that demanded medical treatment in this period encompassed acute respiratory infections, around 10 % abdominal pain and gastroenteritis, while other medical problems were ascribed to only a small proportion of all treated people.

4. Discussion

Slovenia was not prepared for the 2015 migrant wave. Between September 2015 and March 2016, approximately 470.000 migrants and refugees crossed Slovenian territory, resulting in a humanitarian disaster and creating a crisis that required close cooperation between numerous governmental and non-governmental organizations. It turned out that during peacetime, healthcare systems are often not prepared for extreme events such as the 2015 migrations. Adult applicants for international protection and other migrants are only entitled to emergency medical assistance on account of their status. The health problems of migrants are often excluded from emergency medical assistance, at least by definition and under existing legislation.[13] During the first days of the crisis, existing emergency medical assistance teams provided medical aid to migrants. It was soon evident that the available personnel will not be able to ensure adequate medical treatment for the inhabitants of the municipalities of Brežice and Krško as well as all incoming migrants at the same time. As the situation was new and unexpected, no guidelines or instructions were available on how to best organise and provide assistance to so many people in such a short time. The situation most resembled a mass disaster. In accordance with the guidelines for action in the case of a mass disaster, a coordination group was set up, ensuring work organization and communication with the Ministry of Health. In a very short time, additional teams had to be assembled, as well as sanitary materials and medicine, and an information system established for recording treatments and the amount of materials and medicine used. Even though applicants for international protection are entitled to emergency medical assistance, health workers soon face the question of who will pay for all the services provided and to what extent they can even treat the applicant. The healthcare of applicants for international protection is determined by the Act on international protection, which stipulates that the national budget covers the applicants' healthcare expenses.[14] At the beginning of the crisis, the personnel, medicine and materials were provided from the supply of

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[13] Helena Liberšar: Legal framework of the Slovenian healthcare system and access to medical services in Slovenia. In: Helena Liberšar (Ed.), Medical Treatment of asylum seekers. Ljubljana 2017, pp. 65–66.

[14] Liberšar: Legal Framework (Note 3).

Health Centres Brežice and Krško at their own initiative, therefore it was important to set up a system for recording the use of resources, as precise data on costs were required for reimbursement. Because the first wave was so short, there were no official written instructions made available to the coordination group, and most communication took place via email or telephone. However, during this short period, the people responsible were forced to get organized and they were thus better prepared for the second wave.

Official instructions were issued more quickly, plans for various scenarios were drawn up, and persons responsible nominated. Additional people were also mobilised, from local medical residents to medical students, and medical organizations from all over Slovenia. A network of Slovenian voluntary medical professionals was set up. Several international voluntary medical organizations also offered assistance. The healthcare of migrants must be considered from a broader perspective, in the context of their refugee experience (journey, trauma, fear, persecution, mortal danger, etc.), and even in medically non-urgent cases adequate medical treatment, that does not complicate or worsen their health condition, must be ensured.[15] When examining the health problems that made migrants seek medical assistance, we find that acute conditions, which could cause serious consequences if left untreated, were the most common. However, the medical condition of migrants can quickly be improved, with simple measures. As the migrants were at the reception centre for only a brief period of time, by definition a maximum of 72 hours, and in practice they were transported to accommodation centres on the same day, no suspected deteriorating chronic diseases were recorded among the treated illnesses. Wishing to get to their final destination as soon as possible, usually Western European countries, the migrants also kept certain health problems to themselves when entering Slovenia. Considering the length of their journey and the conditions in which they travelled, one would expect to find more injuries and locomotor apparatus issues, but the migrants probably mostly withheld these problems due to the aforementioned reason and decided to seek treatment at a later point in time. The migrants' mental state is also a distinctive, extremely exposed aspect of their health. Entering a country and starting the process of obtaining international protection first inspires hope for a better life. But during their time at an accommo-

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[15] Liberšar: Legal Framework (Note 3).

dation or asylum centre, the migrants face numerous stressful circumstances, from social isolation, financial uncertainty, loss of their role in society and family, limited access to healthcare, work and other activities, any of which can rob them of their dignity, sense of purpose and hope.[16] More susceptible individuals can thus develop anxiety and depressive disorders, somatisation or start using psychoactive substances. The fact that upon arrival at the reception centre the migrants still hope for a better life, is the key reason that so few psychological issues are recorded. We must also take into account the language barrier that the migrants face. It is hard enough to talk about psychological issues, let alone do it in a foreign language or with the assistance of interpreters.

5. Conclusion

The migrant crisis of 2015 presented a great challenge for Slovenia and Slovenians. Nevertheless, the Slovenian public came together and quickly made the necessary preparations to welcome and attend to the migrants who were oftentimes in poor health. We managed to handle the situation with the maximum activation of all parties, both healthcare providers and volunteers, and make all the necessary arrangements in only a few days to be able to receive and treat migrants. When treating migrants, it proved essential to address healthcare in a wider context, especially with regard to their journey and the circumstances that made them leave their homeland. We must also account for the possible differences in perceiving medical conditions, their religious beliefs and the language barrier, which we were able to overcome quite efficiently with interpreters.

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[16] Liberšar: Legal Framework (Note 3).

Robert Bitterlich, Heike Vogelbusch, Stephanie Schierack, Jana Luntz

The refugee guide as an innovative project: Development, implementation and use at the University Hospital Carl Gustav Carus Dresden

Abstract

In recent times, hospitals in Germany face new challenges related to the rising number of refugees and their medical treatment. The biggest challenges pose vague administrative processes and the language barriers. To tackle these challenges, the University Hospital Carl Gustav Carus Dresden (UKD) initiated an innovative project named »Refugee Guide« (»Flüchtlingslotse«). The »Refugee Guide« project offers refugees easy access to university healthcare and thus promotes their integration. This project is unique among the German hospitals and optimizes the healthcare of refugees in Dresden. The aim of this report is to describe the development, experiences of implementation and use of the project at the University Hospital Carl Gustav Carus Dresden. The data was collected through two surveys among employees at the University Hospital. The results of the surveys show that the work of the refugee guide received a high appreciation among the employees of the University Hospital. Moreover, the project optimizes the healthcare provision for refugees in Dresden. Implementation of the project was successful and led to full operation of the »Refugee Guide«. However, this could not be achieved without the mutual support of internal and external partners in Dresden.

1. Background

In 2015, the number of refugees in Germany rose rapidly. In particular, this was noticeable in Saxony's capital Dresden. A big challenge in this situation was, and still is, the provision of healthcare for refugees. On the one side, refugees at the moment of arrival in Germany did not automatically have an entitlement to health insurance. In order to receive medical care, they first needed to apply to the responsible social welfare office. This significantly prolonged the administrative process. On the other side, contact with and the responsibilities of cost bearing authorities were partially unclarified. Also, the language barrier hindered these processes enormously. Furthermore, doctors and nurses needed to take over administrative tasks and were less available for their main occupation. These all factors impeded refugees' access to university medicine.

Against this background, the charity run »Run & Roll – Dresden moves!« was organized in autumn 2015 under the patronage of Petra Köpping, the Saxon State Minister for Equality and Integration and Dirk Hilbert, the Mayor of Dresden. The amount of € 75,000 raised through this charity was used to implement a central case manager to support the healthcare of refugees at the University Hospital Dresden. At this time, such project was an innovation.

2. Preparation of the project

The idea for the »Refugee Guide« arose primarily from the pure observations of clinical practice at the University Hospital Dresden and had to be objectively evaluated over the course of the project. In order to provide a goal-oriented and efficient implementation in the clinical setting, several questions were formulated at the beginning: What are the problems and support needs of the employees providing healthcare for refugees at the University Hospital Dresden? Which clinical structures have the greatest need for support? How effective is the work of the refugee guide at the University Hospital Dresden? The main goal of the evaluation was to involve all employees working directly with refugees into this project and to establish a tailor-made guide position for long-term success.

The project officially started on 26.10.2015 and was divided into three phases. The first phase included several steps. In the first step, an employee survey was conducted on the need for support in caring of refugees in all out- and in-patient wards and emergency departments of the University Hospital Dresden. The aim of this survey was not only to identify the need for support, but also the problems associated with refugee care and thus to confirm the need for a coordination center.

A total of 71 people participated in the October 2015 survey to identify support needs, including 17 physicians, 44 nurses and 10 medical assistants. The majority of respondents reported an increased number of refugees. It became clear that there were a greater number of refugees in the out-patient wards and emergency rooms, than in the in-patient wards. On the other side, it has been confirmed that document management, the organization of interpreters, the clarification of cost bearers and the application for cost cover in particular are regarded as difficult and time-consuming. The additional time required to carry out these organizational needs was estimated to be seven to ten minutes more for the care of a refugee patient, than for a local patient. Due to this comprehensive problem situation, a number support needs were indicated by the participants of the survey. Particular tasks, for which support was required, and their percentual distribution are presented in the Figure 1.

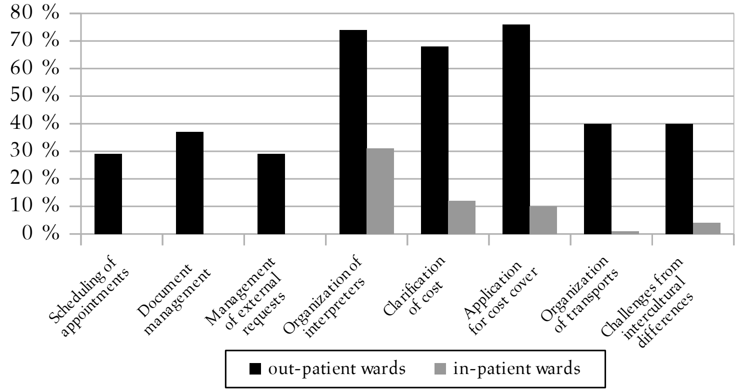

Figure 1: Activities requiring support

Since all of these activities proved to be very time-consuming for the employees and the wish for more support was expressed, it was considered to create the position of a refugee guide, who would support the clinic staff by taking over organizational tasks in the daily medical care.

Subsequently, these survey results were used for the job description of the refugee guide. A qualified employee of the staff from the hospital, Robert Bitterlich, was appointed for this position. Due to the new requirements of this position and in preparation for the implementation, Mr. Bitterlich created an extensive network both in and outside the hospital, i. e. Saxony Regional Directorate, Social Welfare Office, Community Interpreter Service, Refugee Reception Center and the German Red Cross, to establish cooperation with these institutions and to improve the transition management.

3. Implementation of the project

After thorough preparation, the project could move on to the initial implementation phase on 4. 1. 2016. In the implementation phase, the refugee guide Robert Bitterlich was able to start his work as a central case manager in full time at the University Hospital Dresden. To prove the effectiveness and target achievement of the implemented project structure, an accompanying evaluation was carried out over a period of two months. After successful evaluation, the project status was upgraded and implemented as a regular service.

According to the needs, the following main tasks were defined for the guide:

1. Clarification of cost bearing authorities, filing of applications for cost cover in emergency cases and planned in-patient and out-patient hospital treatments
2. Organization of interpreters
3. Assessment about the necessity to be treated in the University Hospital, in cooperation with the medical staff
4. Organization of treatment and admission appointments and monitoring of the treatment process
5. Clarification of social needs of refugees in cooperation with the clinic's social service and external social workers for refugees
6. Counselling of external and internal partners
7. Creation of a network for the medical care of refugees

Additionally, secondary tasks were defined, which encompassed collection and maintenance of evaluation data as well as the medical and administrative documentation of cases according to the guidelines of the University Hospital Dresden. The aim was to reduce the barriers for access to healthcare for refugees, to enable resource-saving care by bundling all inquiries to a coordinating office and at the same time to increase the quality of care through efficient communication.

After four months of testing, a project evaluation was carried out. In the period from 24. 5. 2016 to 3. 6. 2016 a total of 81 persons (response rate 16.07 %) from all units of the University Hospital Dresden participated in a conducted survey. These included 7 physicians, 37 representatives of nursing staff, 20 medical assistants, 9 patient admission staff members, 5 social service staff members and 3 clerks from the Finance Division. The assessment showed extremely positive approval rates.

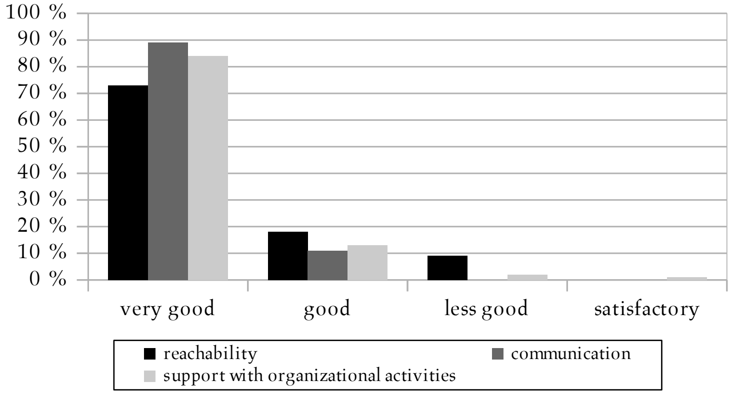

Figure 2: Performance evaluation of the refugee guide

These numbers show that the evaluation of the project was clearly positive. All surveyed professions see the greatest benefit for the refugees, but also for themselves, through the provided facilitation of work. Overall, it is clear that the refugee guide project is accepted and used by the majority of respondents. The effectiveness of the refugee guide at Dresden University Hospital, i. e. the success of the project so far, is confirmed by the good to very good results. The bundling of competences in one hand leads to a considerable relief for healthcare professionals.

The project was meant to be sponsored initially by donations. After the evaluation of April 2016, the Director of Nursing, Dipl.-PGW Jana Luntz decided to terminate the project status early and to finance the refugee guide fully out of the clinic's budget. The remaining donation funds were dedicated completely to pay for the fees of interpreters. Interpreter's fees are in general not paid for by any other cost-bearing authority. Currently and in the future, the refugee guide will play a key role in the medical care of refugees within the hospital. The direct care is provided by doctors, nursing staff and/or therapists. The refugee guide department is responsible for the organization of the feasibility of the treatment, e. g. by organizing interpreters or applying for medical services in consultation with the medical service. The position is also the link between departments of the clinic, general practitioners outside the hospital, refugee social workers and other stakeholders in Dresden. This coordinating role essentially corresponds to the Case Management concept as defined by the German Society for Care and Case Management (DGCC). This procedure is already used in the German hospital landscape as well as in the German healthcare system in many areas, but not yet nationwide.

Overall, the project was a success and is in full operation. The refugee guide and colleagues are further determined to support internal and external partners and people seeking our help. No end in sight!

Funding

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III. Poverty and vulnerable groups

Ines Gumilar, Erika Zelko

Socio-economic structure of patients and their reasons for visiting pro bono clinics in Slovenia

Abstract

Background: In every country are groups of people who have trouble accessing health services, therefore they are categorized as vulnerable groups. In Slovenia, several towns have pro bono clinics for these groups, but the knowledge about them is very poor. In our research we have set out to analyse users of these clinics.

Methods: We carried out a cross-sectional research in four pro bono clinics in Slovenia with the questionnaire. The data collection lasted from the beginning of March 2019 until the end of October 2019.

Results: Among visitors of the clinics 48.3 % were unemployed, 61.7 % are non-Slovene citizens, 68.3 % do not have a permanent residence and 68.3 % of them have been visiting the clinic for more than a year. The most common reason for visiting the clinics are acute diseases. 96.7 % of patients treated in the clinics were very satisfied with the treatment.

Conclusion: Pro bono clinics in Slovenia are mostly visited by patients from vulnerable groups who have also most difficulty in accessing health services. In our study, we found no differences in disease between the at-risk vulnerable group and the general patient population.

1. Introduction

The term »pro bono publico« (abbreviated »pro bono«) comes from Latin and means good for the people. This is not traditional volunteer work, but it is about professionals from different fields (e. g. law, health, medicine) offering specific services to those people who cannot afford them.[1] In the field of healthcare, there are pro bono clinics

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[1] Merriam-Webster: pro bono. https://www.merriam-webster.com/dictionary/pro%20bono (accessed 14. 9. 2019).

intended for people without health insurance. These people mostly belong to special groups of the population, which can be called »vulnerable« (lat. vulnerabilis) groups and thus indicate both the »vulnerability« of their bodies or greater susceptibility to certain diseases and their exclusion in the health system and society. Vulnerable groups are considered to be very heterogeneous, consisting of migrants, the homeless, the elderly, drug users, the unemployed, people with mental health problems, Roma, the self-employed, people with precarious employment and people with various forms of disability.[2] In many countries like the United States of America (USA), pro bono health services are the ethical responsibility of healthcare providers who try to provide fair care and non-discriminatory treatment to all, especially if the health insurance is a privilege, not a basic right. The study of Khan found out, that the policy »(…) has created large sector of socio-economically disadvantaged people who live in the USA who do not qualify for healthcare and are largely unable to afford access to healthcare services.«[3] In 2017, 27.4 million (10.2 %) adults (0–64 years) were registered without health insurance. The most common reason for this was excessive financial costs (44 %), followed by job loss or change of employment (22 %). The majority of uninsured people were adults (19–64 years old), in working families (at least 1 family member is employed) and in low-income families. Significantly higher rates of uninsured adults were among Latinos (19 %) and blacks (11 %) compared to whites (7 %).[4]

Unlike the USA, health insurance is universal in the United Kingdom (UK). This means that all residents of the UK are automa-

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[2] Uršula Lipovec Čebron, Marjeta Keršič Svetel, Sara Pistotnik: Zdravstveno marginalizirane – »ranljive« skupine: ovire v dostopu do sistema zdravstvenega varstva in v njem [Marginalized health groups – »vulnerable« groups: Barriers to access and within the health system]. In: Jerneja Farkaš-Lainščak (Ed.): Ocena potreb uporabnikov in izvajalcev preventivnih programov za odrasle: ključni izsledki kvalitativnih raziskav in stališča strokovnih delovnih skupin [Assessing the needs of users and providers of adult prevention programs: key findings from qualitative research and the views of expert working groups]. Ljubljana 2016, pp. 14–25.

[3] Lori Khan: A Study on Legal and Ethical Issues Surrounding Health Practitioner Pro Bono Services. In: The Online Journal of Health Ethics 6 (2010), https://doi.org/10.18785/ojhe.0602.01.

[4] Jennifer Tolbert, Kendal Orgera, Natalie Singer, Anthony Damico: Key Facts about the Uninsured Population. Henry J Kaiser family foundation, Issue Brief 2019. https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/ (accessed 15. 9. 2019).

tically entitled to healthcare services, which is mainly free of charge at the point of care. For people, such as non-European visitors and undocumented immigrants, only the treatment of emergencies and certain infectious diseases is free.[5]

However, the organization Doctors of the World, which operates worldwide, notes that even in the UK many people (especially asylum seekers, vulnerable migrants and those unable to pay for healthcare) do not have access to public health services or they are often rejected by primary care staff.[6] Similar situation is also in Germany, where the Ärzte der Welt (Doctors of the World) operates.[7] In Germany refugees and undocumented immigrants are covered by social security in cases of acute illness and pain, as well as pregnancy and childbirth.[8]

The problems associated with vulnerable groups and healthcare are not only present in the UK and Germany but also several other European countries. The study, conducted in as many as 14 European countries from 2007 to 2010, examined the experiences and views of mental health professionals for six socially vulnerable groups. Four components have been identified that represent good practice in the field of mental health: setting up programs to raise awareness and work with people about mental disorders; facilitate access to services; strengthening cooperation and coordination between different services; disseminating information about services to both vulnerable groups and health professionals in the area. All this reflects common features in countries and groups, despite the differences between them, and can therefore be understood as generally applicable.[9]

Difficulties in accessing healthcare are also encountered in the countries of the African continent. One of them is certainly Uganda, where many poor people cannot afford to pay directly for healthcare. To improve access to healthcare for these people, Community Based

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[5] The Commonwealth Fund: International Health Care System Profiles. https://international.commonwealthfund.org/features/who_covered/ (accessed 16. 9. 2019).

[6] Ärzte der Welt: Menschen ohne Krankenversicherung. https://www.aerztederwelt.org/wem-wir-beistehen/menschen-ohne-krankenversicherung (accessed 26. 9. 2019).

[7] Ärzte der Welt: Menschen ohne Krankenversicherung (Note 6).

[8] The Commonwealth Fund: International Health Care (Note 5).

[9] Stefan Priebe, Aleksandra Matanov, Ruth Schor, Christa Straßmayr, Henrique Barros, Margaret M. Barry, José Manuel Diaz-Ilalla, Edina Gabor, Tim Graecen, Petra Hocnerova, Ulrike Kluge, Vincent Lorant, Jacek Moskalewicz, Aart H. Schene, Gloria Macassa, Andrea Gaddini: Good practice in mental health care for socially marginalised groups in Europe: a qualitative study of expert views in 14 countries. In: BMC Public Health 12 (2012), https://doi.org/10.1186/1471-2458-12-248.

Health Insurance has been introduced as recommended by the World Health Organization. The impact of this measure on human health was demonstrated by a study conducted between January 2015 and June 2017 in rural south-western Uganda. The results showed that during this time, the introduction of voluntary health insurance in the community increased the use of healthcare and reduced mortality of children under 5 years of age.[10]

In Slovenia, health insurance is compulsory and voluntary. The scope of the first is determined by the Health Care and Health Insurance Act.[11] However, some people may experience limited access to the healthcare system. The right to cover the contribution for compulsory health insurance in the case of socially disadvantaged people is not an independent right, but is conditioned by other rights, it is influenced by any of the reasons for not receiving cash social assistance.[12] In recent years, the economic crisis has led to an increase in the number of people unable to pay contributions for compulsory health insurance (abbreviation in Slovene OZZ), and therefore an increase in the number of people with reserved rights to health services, but still Slovenia provides funds for emergency treatment from the budget for all persons, including foreigners, who are not included in the OZZ and are not insured in another country.[13]

According to the Health Insurance Institute of Slovenia in September 2018 were 651 persons without OZZ. This relatively small number is possible, because of co-financing of assistance, counselling and care programs for persons without compulsory health insurance that started in 2017 with the key objective of reducing the number of persons without compulsory health insurance, and increasing the

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[10] Nahabwe Haven, Andrew E. Dobson, Kuule Yusuf, Scott Kellermann, Birungi Mutahunga, Alex G. Stewart, Ewan Wilkinson: Community-Based Health Insurance Increased Health Care Utilization and Reduced Mortality in Children Under-5, Around Bwindi Community Hospital, Uganda Between 2015 and 2017. Frontiers in Public Health 6 (2018), https://doi.org/10.3389/fpubh.2018.00281.

[11] Amendments to the Health Care and Health Insurance Act 2019. Official Gazette of Republic Slovenia No. 36/19.

[12] Martina Bofulin, Jerneja Farkaš Lainščak, Karmen Gosenca, Ajda Jelenc, Marjeta Keršič Svetel, Uršula Lipovec Čebron, Sara Pistotnik, Juš Škraban, Darja Zaviršek: Kulturne kompetence in zdravstvena oskrba: priročnik za razvijanje kulturnih kompetenc zdravstvenih delavcev [Cultural competences and health care: a handbook for developing the cultural competences of health professionals]. Ljubljana 2016.

[13] Bofulin, Farkaš Lainščak, Gosenca, et al.: Kulturne kompetence (Note 2).

transition of uninsured persons to the public health system.[14] According to data for 2021, in Slovenia, more than 130,000 people had no access to a general practitioner.[15]

The first pro bono clinic started operating in January 2002 and still operates successfully today.[16] The former head of the pro bono clinic Alexander Doplihar found out that the most common diseases of users of this clinic are: diseases related to the inability to take care of personal hygiene, diseases associated with excessive alcohol consumption, smoking-related diseases and mental health problems.[17]

There are currently seven pro bono clinics existing in Slovenia. Four of them were included in the research: the pro bono clinic in Koper, the Mobile Asylum Clinic in Ljubljana, the outpatient clinic for persons without compulsory health insurance with a consultation room – Maribor and the pro bono clinic in Murska Sobota/Tišina.

The purpose of our research was to determine the socio-economic structure of patients who visit these pro bono clinics in Slovenia and the reasons for their visits, as the knowledge of patients who visit these clinics in Slovenia is very poor.

2. Methods

We carried out a cross-sectional research in four pro bono clinics (Koper, Maribor, Ljubljana – mobile refugee clinic and Murska Sobota/ Tišina). The subjects were patients who visited the above-mentioned pro bono clinics and agreed to participate in the study, which means that they solved a paper questionnaire when visiting the clinic. The data collection lasted from the beginning of March 2019 until the end of October 2019.

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[14] Public tender for co-financing of programs of assistance, counselling and care for persons without compulsory health insurance, for the years 2017 and 2018. Official Gazette of Republic Slovenia No. 3/2017.

[15] Sarah Neubauer: Iskanje osebnega zdravnika je skoraj misija nemogoče. N1SLO, 26. 6. 2021. https://n1info.si/novice/slovenija/osebni-zdravnik/

[16] Ambulanta s posvetovalnico za osebe brez zdravstvenega zavarovanja, Pro Bono [An outpatient clinic with a counselling centre for people without health insurance, Pro Bono]. https://www.ordinacija.net/members/www-pzs.php?mg_pzs_id=74&lang = (accessed 17. 9. 2020).

[17] Bofulin, Farkaš Lainščak, Gosenca, et al.: Kulturne kompetence (Note 2).

Confirmation and consent for the implementation of this quantitative descriptive research was given by the Commission of the Republic of Slovenia for Medical Ethics on 21 February 2019 under number 0120–379/2018/9.

Data were collected using a two-part questionnaire. The first part (Demographic data) was compiled with the help of the manual Methodological explanations – Socio-economic characteristics of the population and migrants, published by the Statistical Office of the Republic of Slovenia.[18] In this part, we asked patients about demographic data: gender, age, education, activity status, citizenship, country of birth, mother tongue, understanding of the Slovenian language and residence. The second part (Reasons for visiting the clinic) was compiled by us. This part of the questionnaire was completed by the patients together with the doctor. We asked them how many times they visited the clinic, how long they have been visiting it, why they visited it that day when they filled out the questionnaire, what disease (or diseases) they have and how satisfied they are with the visit to the clinic. The doctor filled in the part of the questionnaire where the diagnosis of the disease had to be written in words or with a code from the MKB-10 classification.

The questionnaire was first validated on 20 randomly selected patients who visited the family doctor's clinic at the Gornja Radgona Health Centre. Each subject (patient) received a questionnaire in Slovene in paper form when visiting the pro bono clinic. The first part of the questionnaire was completed by the patients themselves, and the second part together with the doctor. If any of them had difficulty completing the questionnaire (poor understanding of the Slovenian language, poor literacy), the person was assisted in completing it by the head of the clinic or another employee in the pro bono clinic (nurse, volunteer) appointed by the head of the clinic and we previously educated him on how to help complete the questionnaire. Each subject completed the questionnaire only once, but not during repeated visits to the clinic.

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[18] Barica Razpotnik: Methodological explanation. Socioeconomic characteristics of the population and migrants (2017). https://www.stat.si/StatWeb/File/DocSysFile/8351 (accessed 21. 10. 2019).

3. Results

The study involved 60 patients from four pro bono clinics in Slovenia. Patient demographics are given in Table 1.

	n = 60	%
Gender		
Male	34	56.7
Female	26	43.3
Education		
incomplete primary school	21	35.0
primary school	8	13.3
vocational school	11	18.3
secondary vocational or high school	17	28.3
college	3	5.0
	AV±SD	range
Age in years	43.7±18.1	7–86

Table 1: Patient demographics (AV = average value; SD = standard deviation)

Most patients were in age group 30–39 years 20 %, then 40–49 years 18.3 % and 50–59 years 15.0 %, less were in other age groups: < 64 years 13.3 %, 60–64 years 11.7 %, 20–29 years 10 %, < 15 years 6.6 % and 15–19 years 5.0 %. In activity status, the results showed that 5.0 % patients were employed, 48.3 % were unemployed, 8.3 % were pupils or students in high school, 1.7 % were students in college, 6.7 % were retired and 30 % were other.

Among the patients, there were 3 (5 %) statelessness patients, 21 (35 %) patients with Slovenian citizenship and 36 (60 %) patients who had other citizenship: 1 patient had USA (United States of America) citizenship, 1 Ukrainian, 9 Serbian, 1 Slovak, 1 Syrian, 3 Northern Macedonian, 1 Russian, 2 Romanian, 1 Moroccan, 3 Kosovo, 1 Iranian, 2 Croatian, 1 French, 1 Eritrean, 2 Bulgarian, 3 Bosnia and Herzegovina (BIH) and 3 patients had Afghan citizenship. Some patients have changed citizenship because the country of birth was not the same as current citizenship. According to the country of birth, the results showed that 2 patients are born in Union of Soviet Socialist Republics (USSR), 4 in Serbia, 20 in Slovenia, 1 in Syria, 3 in Northern Macedonia, 1 in SFRY (Socialist Federal Republic of Yugoslavia), 2 in Romania, 2 in Germany, 1 in Morocco, 1 in Hungary, 8 in Kosovo, 1 in Iran, 2 in Croatia, 1 in France, 1 in Eritrea, 1 in Montenegro, 1 in Czechoslovakia, 2 in Bulgaria, 3 in BIH and 3 patients are born in Afghanistan.

Only 30 % of the pro bono clinics visitors used Slovene as their mother tongue. Other mother tongues were: Serbian 21.7 %, Bosnian 6.7 %, Farsi/Dari 6.7 %, Croatian 5 %, Macedonian 5 %, Albanian 5 %, Bulgarian 3.3 %, Romanian 3.3 %, Russian 3.3 %, Arabic 3.3 %, Czech 1.7 %, Hungarian 1.7 %, French 1.7 % and Eritrean 1.7 %. Among those visitors to the pro bono clinics whose mother tongue was not Slovene: 40.5 % understood and spoke Slovene well, 28.6 % understood Slovene, but didn't speak it well or didn't it speak at all, 16.7 % understood and spoke Slovene poorly and 14.3 % didn't understand or speak Slovene at all.

68.3 % of patients were without permanent residence in Slovenia. Among these patients 26.7 % had temporarily residence, 28.3 % had unreported residence, and 13.3 % had other.

Regarding the frequency of visits to pro bono clinics: 76.7 % of patients visited the clinic at least three times, 15 % visited the clinic twice and 8.3 % visited the clinic just once.

The results regarding the duration of visits to pro bono clinics are: first visit 8.3 %, up to 2 weeks 5 %, up to 1 month 5 %, 12 months or less 13.3 % and more than 1 year 68.3 %.

The most common reason for visiting pro bono clinics among visitors was acute diseases 38.3 %. Other reasons were: exacerbation of a chronic disease 18.3 %, chronic and emerging problems 18.3 %, prescription recipe 16.7 %, control visit 11.7 %, mental health problems 10 % and other 6.7 %.

For the reasons for visiting pro bono clinics, we also analysed the frequency of individual groups of diseases between acute and chronic diseases. Among the patients, 30 acute medical conditions were recorded and classified into groups: respiratory diseases 23.3 %, infectious diseases 23.3 %, injuries 16.7 %, skin and subcutaneous tissue disorders 13.3 %, gastrointestinal diseases 10 %, urinary tract and genital diseases 10 % and symptoms, signs 3.3 %. Among chronic diseases, circulatory diseases were the most common 28.8 %, then mental and behavioural disorders 21.2 %, endocrine diseases 15.2 %, diseases of the musculoskeletal system 6.1 %, skin and subcutaneous tissue diseases 6.1 %, infectious diseases 4.5 %, eye diseases 3 %, urinary and genital diseases 3 %, gastrointestinal diseases 3 %, neoplasms 3 %, nervous system diseases 3 %, blood diseases 1.5 % and ear diseases 1.5 %.

Visitors of the clinics were very satisfied with the treatment in 58 cases (96.7 %) and gave a grade of 5, one patient gave grade 4 (satisfied) and one patient gave grade 3 (moderately satisfied). No one gave grade 2 (not satisfied) and grade 1 (not at all satisfied).

4. Discussion

4.1 Discussion of results

The majority of patients attending pro bono clinics (hereinafter referred to as patients) are male, with lower education (incomplete primary and primary education) and the working age population (15–64 years), but also the majority are unemployed, without permanent residence and those who they do not have Slovenian citizenship. We would also like to draw attention to the second most common response to the status of »other« activities (Table 1), which included recipients of social and other benefits and allowances, family members of insured persons (housewives), recipients of state pensions, other inactive persons registered for health insurance and migrants. This described group of patients belongs to vulnerable groups of the population already described. We could conclude that pro bono clinics in Slovenia are mostly visited by patients who are »vulnerable« and have the most barriers to accessing health services. An additional obstacle for these patients is the language, as most patients do not speak Slovene as their mother tongue and most of them do not understand or speak Slovene, so they also needed help in solving the questionnaire and were helped by people working in pro bono clinics (nurses, doctors or volunteers).

Mostly, patients are multiple visitors (they visited the clinic for the third or more time) and long-term (they visit the clinic for more than 1 year). This may indicate that it is not so easy to arrange health insurance in short time and therefore they remain marginalized in society or »vulnerable«. Thus could also make them more susceptible to certain diseases. Further research would be needed to assess the reasons why they have not been able to regulate their status for a relatively long time. When analysing disease diagnoses, we considered only physician codes from the ICD-10 classification; as many times the patient's self-reported disease did not match the doctor's record, and also the doctors mostly recorded more diagnoses than the patient. The most common reason for visiting the clinic among patients were acute illness, and among these on the first place were infectious and respiratory diseases, which is similar to a regular family doctor's clinic – where are the most common reason for visiting acute respiratory disease.[19] Viruses are the most common cause of acute respiratory infections,[20] so it can be assumed that respiratory infections also occurred in the group of infectious diseases and among patients of pro bono clinics are the most common respiratory infections as well as in the family doctor's clinic. Among chronic diseases, they were in first place circulatory diseases. Circulatory diseases or cardiovascular diseases have been the most common cause of morbidity and mortality in adults in the developed part of the world and in Slovenia for decades.[21] Patients who visit pro bono clinics mostly belong to the adult population and are therefore similar to other patients in Slovenia in terms of the most common chronic disease. On the second place in pro bono clinics patients are mental disorders. This result is to be expected, as vulnerable groups also include people with mental disorders.[22] On third place in chronic diseases are endocrine diseases, among which all but one response (hypercholesterolemia) was diabetes. The National Institute of Public Health (NIJZ) finds that diabetes, as one of the chronic diseases, is not only a problem of the developed world, but is increasingly a reflection of economic and social determinants of health, such as poverty and lack of education.[23] In our research, this two determinants of health were found to be the most common in pro bono patients.

With our research we can confirm that most patients were very satisfied with the treatment in pro bono clinics, which indicates a

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[19] Igor Švab, Rotar Pavlič: Družinska medicina: Priročnik za mentorje študentov [Family Medicine: A Handbook for Student Mentors]. Ljubljana 2012.

[20] Švab, Rotar: Družinska medicina (Note 8).

[21] Nacionalni inštitut za javno zdravje: Srčno-žilne bolezni [Cardiovascular diseases]. https://www.nijz.si/sl/srcno-zilne-bolezni (accessed 22.12.2019).

[22] Lipovec Čebron, Keršič Svetel, Pistotnik: Zdravstveno marginalizirane (Note 2).

[23] Nacionalni inštitut za javno zdravje: Sladkorna bolezen [Diabetes]. https://www.nijz.si/sl/sladkorna-bolezen (accessed 22.12.2019).

well-organized clinic with friendly staff who have a respectful attitude towards these patients.

4.2 Discussion of methodologies and research limitations

Two questions from the first part of the questionnaire were excluded from the analysis: previous and future citizenship, as more than half of the patients did not solve these questions. Additional analyses would be needed to determine why patients did not want to answer these two questions.

The problem was also the language in some places, as the questionnaires were written only in Slovene. Some problems caused also the illiteracy of some of the patients. We solved it by assisting patients (translating, writing answers) in individual clinics with the supervisors or with the medical personal – chosen by supervisors, if patients allowed it and the confidentiality of the data was maintained.

One of the limitations of our research is also the small sample of patients. So, we could not generalize the conclusion of our research. With a larger sample we also may showed links between patient's demographics and their illnesses. Other pro bono clinics in Slovenia could be included in the research in order to obtain more accurate data for the whole of Slovenia, as well as various comparisons between clinics with larger samples of individual pro bono clinics. This would better represent the condition of patients in pro bono clinics in Slovenia and the needs of these clinics in terms of staff, supply of materials, medicines, aids, etc., and at the same time this could be the basis for policy to solve their problems with health insurance and consequently reducing health inequalities.

5. Proposals

It would be good if pro bono clinics worked with social services to help patients with financial care, housing, and finding jobs, as many patients are socially at risk. Pro bono clinics, in addition to the equipment that family medicine clinics have, also need a set of drugs to treat the most common acute and chronic diseases. We could also explore which medicines are most commonly used in pro bono clinics so that these clinics can secure a range of unused medicines from healthcare facilities or from other patients in advance. Patients who do not have health insurance also visit the family doctor's clinic on a regular basis. In the event that a patient does not need urgent treatment, family medicine teams should know the place and working hours of the nearest pro bono clinic to which they can refer these patients. Medical teams could be involved in the work of pro bono clinics if the need arises – this could be the subject of future research on pro bono clinics.

6. Conclusion

Pro bono clinics are still needed in Slovenia and mostly have to operate regularly, at least once a week. At work, they need staff who – in addition to medical knowledge – are also proficient in communication and approach to less educated and illiterate patients, be able to communicate in some foreign languages, especially languages from the former Yugoslav member states, or provide a translator and develop cultural skill competencies.

Vida Drame Orožim

An outpatient clinic and counselling assistance for people without health insurance, Ljubljana, Slovenia

Abstract

The Pro Bono Outpatient Clinic (PBC) provides medical and counselling assistance to people who are not included in the existing national healthcare system. We offer free health services in cases of life-threatening diseases, conditions, and injuries to people residing in the territory of the Republic of Slovenia. The outpatient clinic was established by the Community Health Centre Ljubljana, the City Municipality of Ljubljana and Slovene Philanthropy. Thanks to them, we have three full-time employees, and outpatient facilities which are under the authority of the Bežigrad Health Centre Unit. Given the variety and richness of our work, the clinic can easily be named a small volunteer polyclinic. The work is performed completely differently than in conventional, general or specialist clinics due to certain characteristics which are set out below.

1. Description of the organisation and characteristics of the Pro Bono Clinic

The characteristics of our clinic are as following:

1. Volunteer work
2. Flexible teamwork
3. Marginalised patient population
4. A broad social network of work colleagues

The first characteristic of our clinic is that all doctors work here on a voluntary basis. Why do I stress that? In conventional clinics, public or private, the income of medical staff represents one of the highest expenditures. In the case of our pro bono clinic, this cost is completely eliminated. Volunteer work is performed by approximately 20 doctors of various specialties. The number changes because volunteers leave and others come according to their other commitments and obligations.

The Pro Bono Outpatient Clinic (PBC) operates at the:

a. primary
b. secondary
c. tertiary level

At the primary level, general healthcare activities are performed by a General Practitioner (GP) or other medical specialists. At the PBC, initial and follow-up medical check-ups are performed. In doing so, the work is performed in the manner required by the established medical doctrine. In the first place, anamnesis and heteroanamnesis should be taken, which usually represents a problem for foreigners from the Middle East and Far East, especially if they speak poor English. Once we have at least a basic medical history, and after a clinical examination is performed and a diagnosis established, a patient is referred to tests (if necessary) and given appropriate therapy. In the case of conditions that cannot be resolved at the primary level, the patient is referred to an appropriate specialist working at the secondary level.

The work at the secondary level is performed by specialists of individual professions. If the primary care physician determines the need for a second specialist examination, the registered nurse is instructed to collect a certain number of patients and call the appropriate specialist to perform the work at our clinic at an agreed time. For instance, a gynaecologist, an internist, a neurologist, a radiologist, a paediatrician come to our location at an agreed date, and they perform check-ups, determine the necessary examinations and therapy or refer a patient to another specialist at a tertiary level. Unfortunately, due to the lack of space, we cannot render it possible for ophthalmologists and dentists to work at our clinic, because they need specific medical equipment and space for their work. In cases where specialists work elsewhere, for example in their own medical practices, and do not come to our clinic, we send our patients to the doctors' location where they are treated by the required specialist. We have such an agreement with some concessionaires and with individual clinics.

At the level of tertiary activity, the Department of Emergency Medical Care is of great help to us. In emergency cases, they perform the necessary check-ups and examinations, and refer patients to an institution at a tertiary level, which means hospitalisation, demanding examinations, minor and difficult surgical procedures, and other measures. Following treatment at the tertiary level, which was for instance necessary because of a surgical procedure, the patient is referred again to our clinic where they are treated until further notice. We constantly work with specialists from a relevant clinical institution, which is of great professional and moral support to us.[1]

2. The hierarchy and content of medical work

As already mentioned, volunteer work is performed by a large number of doctors. All doctors are specialists who devote some of their time to the benefit of people who do not have the privilege and the opportunity to get the medical care received by most citizens of our country. Some of them work at our clinic a few hours a month or week, perform duties related to their own disciplines, and do not have any other responsibilities. It is therefore essential that one of the physicians is willing to take over the management of the clinic, as she can devote much more time to this function than other physicians. Therefore, it is worth paying a little bit more attention to the PBC manager.

Doctors are present at the clinic for a short period of time, 2 to 4 hours, and in their absence a registered nurse, a social worker, and a housekeeper are present at the clinic. If they need medical advice, they can always consult a doctor by phone. This responsibility is usually in the hands of the PBC head.

3. The role of the PBC head

I can say that the greatest burden and responsibility for the sound operation of the clinic lies on the shoulders of the head of the clinic, who is the one who performs the most working hours per year. The PBC head carries out general healthcare activity, triage, ensures effective team communication and provides professional staff as well as housekeepers with timely information. In addition, the head takes care of staffing, maintenance, social communication, and fosters good interpersonal relations. The head also plays an important role in the education of the professional team, patients, and their relatives.

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[1] Sara Gregori: Poročilo o delu ambulante v letu 2019 za Mestno občino Ljubljana, Oddelek za zdravje [Report on the work of the outpatient clinic in 2019 of the City of Ljubljana, Department of Health]. Ljubljana 2020.

In addition, one should also not ignore her concerns to promote the clinic, thus making the professional and non-professional environment aware of the role and importance of the PBC. The PBC head is also on permanent standby so to speak, during the entire official operating hours of the clinic.

With regard to promotion and recruitment, I need to clarify the following. Occasionally people ask me if it is true that there are only second-class doctors working at the clinic. I am happy and proud to say that our staff are truly highly professional. All the physicians working at the PBC are renowned specialists with many years of experience, senior doctors, PhD holders, and also University professors. They all have the appropriate licenses, many years of clinical experience, and are still active or retired doctors who are, without exception, special people. These are experts who have a high level of social and emotional maturity, are very open, and have the ability to accept differences. They are distinguished by a special value system characterised by a high level of humanity and respect for life.

The late Prof Dr Janez Milčinski, a renowned Slovene forensic medicine expert, was once asked what, in his view, the qualities of a good doctor are. He said that a good doctor is, first and foremost, a good person, who also knows a bit of medicine.

I can say with all certainty that doctors working at the PBC are good people with big hearts and excellent medical knowledge which is becoming increasingly better and more extensive, also on account of remarkable progress in all areas of medicine and other sciences in recent decades.

Nevertheless, it is not only doctors who work voluntarily at the PBC, but also people of other professions such as a physiotherapist, a pharmacist, a nurse, a social media specialist, a midwife, and a lawyer. There is also a psychotherapist offering his services as an external collaborator. All these people are, as regards their personality, just like the volunteer doctors described above. They are people with big hearts who can sense on some very subtle levels, the distress of those from vulnerable, socially disadvantaged groups.

Another special characteristic of our clinic is flexible teamwork. There are at least 4 people who work together on a daily basis: a doctor, a registered nurse, a social worker and advisor on social and legal affairs, a housekeeper, and other profiles if necessary.[2]

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[2] Alenka Ugrin Vatovec: Poročilo o delu posvetovalnice v ambulanti v letu 2019 za

4. A brief description of teamwork and work of individual team workers

A doctor, a registered nurse and a social worker represent professional staff who are responsible for the course of medical activity. There is a constant, up-to-date, horizontal communication taking place between the staff members, which is absolutely essential in order to resolve health-related and social problems of clients efficiently and successfully. The most important element of this work is flexibility.

Teamwork goes well if relations among work colleagues are good, genuine and well- coordinated. Each individual member of the abovementioned professional team works in their area of expertise and regularly consults, adjusts, proposes and informs the other two members about an objective situation which is different for each client. It is practically impossible to establish a routine in teamwork, because of the many unknowns involved in solving the problems of each individual. And these unknowns can only be solved with the assistance of a social worker and, if necessary, with the inclusion of other experts and institutions. Therefore, without flexibility and good mental health and well-being of all employees, such work cannot be carried out.

I mentioned the volunteer work of doctors earlier. Therefore, it is also relevant that other workers – the registered nurse, the social worker, and the housekeepers, are in a regular employment relationship for an indefinite period of time. They are on duty during the entire official working hours of the clinic, even when a doctor is not present. Without them, our healthcare work is impossible to imagine.

The work of the registered nurse represents the foundation of the PBC work. The registered nurse is present every working day, and works full time. In addition to primary healthcare duties (admission of patients, the initial and follow-up check-ups, inspection of identity documents, verification of health insurance, determining the reason for the visit), the registered nurse is also in charge of all administrative work such as: keeping a register of patients, verifying their identity and health insurance, keeping a doctors' attendance schedule and a schedule of control examinations, coordination between doctors and other work-colleagues, scheduling patient appointments, informing patients, writing reports, preparing patients for preventive and cura-

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Slovensko filantropijo [Report on the Work of the Consultation room in the Outpatient clinic in 2019 of Slovenian philanthropy]. Ljubljana 2020.

tive check-ups, participating in examinations, performing biometric and tropometric measurements, performing managerial activities, ordering and administering medicines, being in charge of healthcare education (diabetics, pregnant women, children, the chronically ill), taking care of vaccinations and storage of vaccines, handling waste, ordering medical materials with EDICO application, making sure that Ljubljana Healthcare Centre (ZDL) standards are taken into account, attending trainings and meetings, cooperating with the media, cooperating with similar clinics, obtaining donations, and countless other tasks based on communication with the umbrella organisations of our clinic. The registered nurse has to maintain regular and professional contact with all of them and inform them about the events and activities of the clinic. She also takes care of a wide professional network of medical staff, contacts with pharmacists, nurses. Her work is really highly appreciated since she can really relieve a doctor of the burden, either by doing the work on her own or by consulting a doctor over a telephone.

A nurse and a doctor who are able to facilitate a two-way communication and are willing to take into account each other's suggestions and opinions are an ideal professional partnership. Such communication facilitates the work and increases professional and time efficiency. A compatible relationship is the key to good cooperation, so that everyone gets inspired and is willing to join forces and work together. A nurse who is unable to do so, comes across as unpleasant and annoying, and can cause interpersonal tensions leading to poor quality work and team breakdown.

The work of a social worker requires specific knowledge, particularly in the field of health, administrative, social and civil legislation. It requires the abilities of exceptional tolerance, networking, decision-making, and appropriate communication with people who do not have a valid status and do not meet other conditions applicable in the Republic of Slovenia. After the first contact, the registered nurse redirects them to a social worker who finds out why they are in our country. As regards the patient visits at our clinic, the ratio between the number of Slovenian and foreign citizens has been around 50:50 % all these years.

A housekeeper, who is a non-professional colleague, plays a very important role in our team as well. She is employed as a cleaner, however, she performs her work duties on a wider scale and at a higher level. That is why I named her a housekeeper. Without her assistance, our clinic would not function perfectly. The housekeeper is also included in continuous information flow and coordination. Due to the large fluctuation of people, the housekeeper must ensure a high level of room hygiene. In addition to the outpatient rooms, an office, an isolation room and a warehouse, she must also take care of the toilets and the bathroom which is used by the homeless to wash and change their laundry and swap donated goods. The housekeeper also supplies the homeless with basic hygiene items such as toothbrushes, towels, soap, etc. She is in charge of receiving and sorting all donated clothes and numerous other items, from laundry to orthopaedic aids, trolleys, etc. This person must also surely have personality traits such as respect and tolerance for difference, warm-heartedness, diligence and kindness, which is what the population she communicates with needs.

5. Who are our patients?

The special characteristic of PBC is our patients, who are mostly on the social margins, belonging to particularly vulnerable groups living at the edge of society, the so-called marginalised population. When providing health services, everyone is identified on the basis of their personal documents and other documents, if one has any. If we find out that a patient does not have adequate health insurance, the person is entered in the register of our patients.

Among Slovenian citizens, people visiting our clinic are those with non-existent or unregulated health insurance. These people are mostly from different marginalised categories; people with precarious employment, victims of physical violence, the homeless, addicts, the elderly, foreign students, psychiatric patients, and former prisoners who no longer have health insurance after serving their prison sentence. This group also includes people without valid identification documents. Among the Slovenes, the marginalised groups are represented by former craftsmen, the homeless, addicts, Slovene-foreigner couples, former prisoners, and those without any personal documents.

The first such group are former craftsmen who have unpaid debts to the state, failed crafts or businesses and are not capable of working due to their age or illness. A special category is represented by the homeless, mostly men, rarely women, who are more or less our regular patients, and are addicted to alcohol, drugs or both. Under the Slovenian healthcare system, drug addicts without health insurance are no longer entitled to receive free methadone treatment, therefore, in the state of abstinence crisis they often recourse to our clinic. The next category of patients are former prisoners who, after serving their prison sentence and returning to normal life, no longer have the health insurance they were entitled to during their imprisonment, regardless of their status.

We are occasionally visited by mixed-nationality couples, one of whom is a Slovene and the other a foreign citizen who has fallen ill. The foreign citizen seeks healthcare assistance at our clinic because they both wish to stay and permanently organize their life in Slovenia, but they have not yet arranged all the necessary papers.

We also have cases of patients living in Slovenia for many years, who have no personal documents. They are known to the police who initially fined them, but then eventually left them alone because they have not been causing any trouble. The issue arises when one of them gets ill, and the situation becomes so complicated that such patients end up being passed between various institutions which do not know how to sort out or simply handle their situation. Here, it seems that a systemic solution at the state level is likely to be needed.

Among foreign nationals, there are refugees who have applied for international protection, and other foreigners without residence status. There are also some foreign students and tourists. A social worker tries to help these people, particularly when it comes to sorting out issues with their documents such as arranging and obtaining certificates of temporary and permanent residence or obtaining permission to stay in our territory, certificate attesting the absence of any criminal record, work visa, and last but not least acquisition of citizenship.

Among foreign nationals, there are people who have applied for international protection and/or have unfit living conditions, for instance: migrants who are mostly younger men, tourists who are foreign nationals and find themselves stuck in Slovenia, foreign students, and the elderly visiting their children who have lived and worked in Slovenia for many years. Occasionally, we also deal with victims of domestic violence. These are most often individual cases of young women who have no education, some of them even being illiterate, who are completely financially dependent on their partners, have at least two children and are thus unable to become independent.

Given the diversity of our patients and the specifics of the work, we truly are a very special institution which could also be called a Small Polyclinic of Volunteers. Our patients come from all corners of the world, from all continents, and are of all varieties of religions, skin colours, languages, and cultures: Ecuador, Brazil, Gambia, Eritrea, Algeria, Libya, Iraq, Syria, Russia, Ukraine, Bosnia, Serbia, Croatia, Turkey, India, Afghanistan, the USA, the UK, etc.

When communicating, we use several different languages, sometimes with the help of translators the patients bring with them. Common non-verbal forms of communication with pantomime, hand and foot gestures and facial expressions regularly prove useful as well. Occasionally, patients bring a medical report from their country of origin, however, most patients visit our clinic without any medical records, possibly having only a foreign ID, and besides, they cannot even explain what they want. Sometimes it turns out that their visit is not about a medical problem at all, but a social, cultural or other conflict situation they do not know how to get out of. Some patients speak some basic English, others almost nothing, and there are many who speak only their own language, for instance Arabic, Farsi or Turkish, which makes basic communication and assistance very difficult.

6. Some statistics on visits to the Pro Bono Clinic

As established in the 2019 annual report of the registered nurse, 599 patients were treated at the general outpatient clinic. While working independently, the registered nurse recorded 1.400 visits (consultations, donations, providing information, calls related to bringing medicines and clothes). When examining our patients' medical records, we eliminated those who had already had their health insurance arranged or had died or had not visited our clinic for more than 10 years. We came to the conclusion, that at the end of 2019, there were 911 registered patients in total. Out of 911 patients, 291 have open medical records, and 620 patients have been entered in a special medical book because they visit a doctor less frequently. If their health deteriorates, we also open a medical record for them. Out of 911 registered patients there are 905 adults and 6 children.

As is apparent from the social worker's annual report, there were 1205 visitors who received her counselling service, of whom 89 patients visited the outpatient clinic for the first time in 2019. Among these patients, 16 of them subsequently arranged their health insurance, and 1 patient died.

At the first visit, the patient is treated very thoroughly, therefore the initial treatment includes a visit to the social worker, the registered nurse, and a doctor. Once all the professionals align their opinions and determine how we can provide assistance, we agree on the procedures and possibilities of lending a helping hand to the person in need. During follow up visits, the work is less complicated because the professionals are already familiar with certain data and the procedures can only be further supplemented.

In 2019, we classified the users of our Pro Bono Outpatient Clinic into the following categories:

a. Slovene citizens: 17
    - entrepreneurs with debt resulting from their unpaid contributions: 6
    - self-payers of basic health insurance with retained rights to health services: 1
    - people without a permanent place of residence (often homeless people): 6
    - other: 4

b. Foreigners: 72
    - foreigners with a permanent residence permit: 1
    - foreigners with a temporary residence permit: 32 (based on work: 2, based on family reunification: 11, based on schooling and studies 14, based on other justifiable reasons: 4)
    - applicants for international protection: 13
    - other EU citizens: 8
    - holders of a stay permit: 1
    - other: 18 (persons who are tourists in the Republic of Slovenia: 11; persons without a residence permit: 2; persons who have applied for a residence permit, but a decision regarding their permit has not yet been determined by a competent authority: 3; nullified status of the »erased« – the group of people in Slovenia that remained without a legal status after the declaration of the country's independence in 1991: 2).

Division by gender and age:

- men 35
- women 48
- young girls 4
- young boys 2
- total 89

In 2019, 1205 users were provided with our social work counselling service. Not all of those treated needed medical assistance, but only a consultation with a social worker.[3]

7. The most common health problems of our patients

The most common health problems of our patients are: cardiovascular disease, often arterial hypertension, cardiac problems, chronic respiratory diseases, smoking bronchitis, dyspnoea, pneumonia, tracheitis, laryngitis, alcohol and/or drug addicts, diabetes, oncological diseases, psychological disorders, various addictions, adjustment disorders, anxiety, depression, dementia,[4] endocrine disorders, gynaecological issues, pregnancy care for women, preventive examinations, childhood vaccinations, seasonal virus infections, allergies, dermatological diseases, psoriasis, scabies.

All our visitors are, without exception, special in the sense that they are present in our country, but they do not »exist« administratively and are therefore not entitled to obtain compulsory health insurance. At the end of 2020, there were more than 141,000 people without a general practitioner in Slovenia.[5] As a result, they are also not entitled to the same rights as those who have health insurance. After the first contact, the registered nurse who receives the patient, enters his/her name in the list of patients and takes the basic data. The registered nurse then refers the patient to the social worker who is a counsellor for social, administrative, and other relevant matters. Only after the social worker verifies the patient's identity and establishes

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[3] Alenka Ugrin Vatovec: Poročilo o delu (Note 2).

[4] Združenje psihiatrov pri Slovenskem zdravniškem društvu in Republiški kolegij za psihiatrijo: Navodila za izvajanje psihiatričnih storitev v času epidemije Covid-19 [Instructions for the provision of psychiatric services during the Covid-19 epidemic]. Ljubljana 2020.

[5] Sarah Neubauer: Iskanje osebnega zdravnika je skoraj misija nemogoče. N1SLO, 26. 6. 2021. https://n1info.si/novice/slovenija/osebni-zdravnik/

that the patient does not have health insurance, the patient is referred back to the registered nurse. The registered nurse then refers the patient with the prepared medical documentation to a doctor who determines the need for a medical examination, intervention, therapy, or further procedures. Before the patient sees a doctor, the social counsellor, the registered nurse and a doctor have already exchanged all the necessary information and discussed their opinions.

Any patients who already have health insurance in the Slovenian system are referred to their personal doctor. A special category exists that accounts for patients who have state health insurance, but do not have a personal doctor of their choice because they have never been ill before. We try to help people in that situation as well, one way or another, but one administrative action we cannot provide them is registering for sick leave, since sick leave can only be issued by a personal physician. We still sometimes remain powerless in such situations.

The basic problem with our patients is not really health insurance, but the fact that they are forced to visit us due to their illness, since they have no other choice. At this point, other problems that are essential to survival also often surface. In a state of illness, people rise from anonymity in which they have been listless for months, countless among them for years. They do not have the basic conditions for normal living, permanent employment, housing, money, have substandard or deficient documentation, or they live without any official documents that would prove their identity. In the last year, we have treated two men in very poor health who have never in their lives received any official documents confirming their identity, and so they live, work, and have managed to exist in complete administrative anonymity to the Republic of Slovenia, which might seem completely impossible to us, »normal« Slovenian citizens. Most of our patients belong to the marginalised population of the homeless, »the erased« – the group of people in Slovenia who remained without legal status after the country's declaration of independence in 1991, migrants and refugees. We also have a high number of alcohol and drug addicts as well as former convicts who are released from prison and fail to arrange their insurance. In previous years we assisted quite a lot of Roma people, but now they no longer tend to visit. A special category is represented by mental health patients who lose touch with reality and do not know or are unable to arrange appropriate documentation. We have one other very vulnerable group comprising women and their children who are victims of violence, have no education and are often even illiterate.[6]

8. Volunteers from elsewhere

The special feature of our work is the establishment of a wide voluntary social network of individuals and institutions that are willing to provide free-of-charge assistance. These are people and institutions who are prepared to do voluntary work, regardless of their primary social, political and socio-economic role. We work with a lawyer, a psychologist, a psychotherapist, social workers, doctors, nurses, educators, a pharmacist, a physiotherapist, a midwife. We have also managed to attract private and state health-institutions to take part in our activities. We use their services or advice in if we cannot deal with the situation at our Pro Bono Clinic. We work with a private dentist, a dermatologist, an orthopaedist, and various different clinics such as: The Clinical Department (CD) of Cardiovascular Surgery, CD of Rheumatology, CD of Septic Surgery, CD of Infectious Diseases, the Institute of Oncology, CD of Otorhinolaryngology, the Institute of Microbiology and Immunology, CD of Dermatology and Venereal Diseases, etc. Adria Lab, a private diagnostic laboratory, carries out basic laboratory tests for us. All emergency outpatient clinics of the above listed departments are very efficient and well organised.

In addition to healthcare, there are two other programmes of non-governmental organisations included within the framework of our Pro Bono Outpatient Clinic. Slovene Philanthropy attends to psychosocial care, while the Slovenian Red Cross provides our patients with hygienic supplies. For 25 years, Slovene Philanthropy has been responding to social problems, promoting and developing volunteering as well as intergenerational cooperation. Besides, it has also been working in the area of migration, helping the most deprived and defending human rights.

In addition to the above organisations, we also cooperate with the following non-governmental organisations: Shelter for the Homeless in Ljubljana – we provide them with bedding and clothes, Red Cross,

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[6] Vida Drame Orožim: Lastna opažanja in izkustva 5-letnega dela v ambulanti, od leta 2015 do 2020 [My own observations and experiences from 5 years of work in the clinic from 2015 to 2020]. Ljubljana 2020.

Caritas, Pro Bono Outpatient Clinics in Maribor and Koper, The Missionaries of Love in Ježica (Ljubljana), Kralji ulice (Street Kings), Stigma (a non-profit humanitarian organisation) and others.

The most common social-assistance activities we carry out for our users are as following: arranging basic and supplementary health insurance, arranging personal documents, arranging permanent residence, arranging permanent or temporary residence permits in the Republic of Slovenia, arranging better and more suitable accommodation, job-search assistance, assistance in providing legal aid, escorting patients who need to visit a certain clinic or medical facility, establishing contacts with appropriate institutions, providing information, counselling services, advocacy, psychosocial and psychotherapeutic assistance, fieldwork – visiting our users/patients at home.

As can be seen from the information above, we perform a number of different activities which can be described by means of one single denominator – volunteering for people in need.[7]

9. Conclusion

The outpatient clinic and counselling centre for people without health insurance carries out interdisciplinary activities intended for people without health insurance, people who belong to the most vulnerable social groups.

We provide emergency medical, general and specialist services at a primary, secondary and tertiary level for all patients without health insurance, whether Slovenian or foreign nationals, for adults and children, regardless of their age, gender, education, religion, skin colour, cultural or political affiliation.

These are mostly different marginal categories, failed craftsmen, homeless people, the unemployed, former prisoners, the erased, victims of violence, undocumented people living in Slovenia, the Slovenes who want to establish life in our country together with a foreign national, refugees who have applied for international protection or are without a legitimate residence, foreign tourists and students as well as the elderly staying with their children who have been living and working in our country for a long time. We have not seen any Roma people for many years now.

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[7] Vida Drame Orožim, Lastna opažanja in izkustva (Note 5).

Doctors working at the Pro Bono Clinic perform, without exception, volunteer work, while the registered nurse, the social worker, and the housekeeper are all full-time employees without whom the clinic would not be able to function. At the level of a general outpatient clinic, flexible teamwork is essential, and due to the great diversity of people and their hardships, such work necessitates good mental organisation. Therefore, the work in our general outpatient clinic cannot be compared to outpatient clinics dealing with patients who have regular health insurance, residence and documents. In addition to preventive and curative work and thanks to our highly experienced registered nurse and social worker, we also provide counselling, guidance, educational activities and supervision.

A broad social network makes it possible to tackle unusual and complex medical, administrative, and other situations. We cooperate with health and non-governmental organisations (Red Cross, Caritas) which contribute their share of psychosocial and basic hygiene care. Volunteer work is also performed by a midwife, a lawyer, a physiotherapist, pharmacists, and a PR person.

All our volunteers are considered to be special people with mature emotional intelligence, high socio-moral sense, tolerance and the ability to accept differences. They are warm-hearted people who are open, good and kind. They all love life and dedicate their knowledge and time to less fortunate ones in need.

Nada Gosić, Tajana Tomak

The impact of poverty on the position of vulnerable groups in healthcare – a retrospective study of cases of pregnant women and newborns

Abstract

The multidimensionality and complexity of the phenomena of poverty and health, in this paper, are focused on the research of the impact of poverty on the position of pregnant women and newborns, the already existing vulnerable groups in healthcare. The impact of poverty on the health of pregnant women and newborns requires research on content-methodological perspectives in two scientific fields. The first is the field of biomedicine and healthcare, in which objective facts should be found that prove the impact of poverty on the medical condition of pregnant women and newborns. For this purpose, the results of the research of papers published in the medical database PUBMED, which have connected two keywords: pregnancy and poverty in their titles over the past five years, will be researched, presented, and analysed. The second field is the field of social sciences and humanities that, due to the nature of their definition, should direct health professionals to find an approach that will express moral activity towards pregnant women and newborns in conditions of poverty. In order to achieve this objective, the results of the research of papers published in the Journal of Poverty, which have also linked two keywords: pregnancy and poverty in their titles over the past five years, will be researched, presented, and analysed.

1. Introduction

Theoretical and practical testing of well-known definitions of health forms the foundation of questioning the relationship between poverty and health. The first definition is of the World Health Organisation that defines health as a »state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity«. The second definition of health, which originates from the 1978 Declaration of the WHO in Alma-Ata, proclaims that health is »a state of complete physical, mental, spiritual and social well-being«. Following these definitions, the relationship between poverty and health belongs to the content and methodological scope of those sciences whose theoretical knowledge and results of empirical research offer solutions that would, ideally, eliminate, but realistically, reduce the impact of poverty on health as much as possible. At the same time, the examples from the practical life, such as those mentioned in the article, indicate that poverty and health are the main part of some social and civic approaches and perspectives, such as religious, ideological, political, ethical, educational, artistic, media, etc. Following these considerations, this article will fulfil its theoretical and practical purpose, i. e. the reasons for its emergence, if it a) additionally sensitises professionals, responsible for solving this relationship, and the public to address the situations and problems that arise due to poverty in the field of biomedicine and healthcare. And b) if it points out that while creating practical solutions, different meanings and perceptions of poverty should be taken into account on the individual, professional, institutional, political, and broader social level.

2. The impact of poverty on the medical condition of pregnant women and newborns

Under this subtitle, presented and analysed will be the results of the research on papers published in the PUBMED medical database, which in the last five years in their titles have linked the word poverty to at least one of the following words: pregnancy, pregnant woman, breastfeeding, newborns, and infants. In the past five years, the connection of these words has been found in 17 titles of articles published in this medical database. The research was limited to the selection and analysis of those articles with free access to the entire texts. Therefore, this paper presents the research results published in the 17 mentioned articles. Chronologically, the largest number of articles (7) was published in 2015; four articles were published in 2019, four articles in 2016 and 2020 (two in each year), and one in 2017 and 2018. The research interest of the authors in 2015 was directed to the following topics: racial/ethnic disparities and symptoms of depression among pregnant women living in different types of poverty. The topic was introduced and explained by the authors from the field of family medicine and social work from the USA[1]; experiences of the urban healthcare institutions and services with poverty in pregnancy in South Africa[2]. The authors from the fields of public health, health policy and reproductive health from Africa expressed the interest in this topic; poor sanitary/hygienic conditions linked to adverse pregnancy outcomes in rural India. This topic was addressed by the authors from the field of public health from India and the USA, and an author from the field of infectious and tropical diseases from the United Kingdom[3]; a comparative overview of providing health services to poor pregnant women in rural areas of the two Indian countries, Gujarat and Tamil Nadu, was presented by an Indian author and researcher from the Institute of Public Health[4]; the protocol for the evaluation of a free health insurance for pregnant women from the poor Mbeya region in Tanzania was introduced in co-authorship by the scientists in the field of public health and sanitation and tropical medicine, the first from Tanzania and the second from England[5]; juvenile pregnancies; maltreatment, children negligence and poverty were linked in the work of American authors from two fields, paediatrics – the Department of Adolescent Medicine and the Department of Social Work[6]; childbirth outcomes in conditions of poverty were re-

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[1] Catherine Cubbin, Katherine Heck, Tara Powell, Kristen Marchi, Paula Braveman: Racial/Ethnic Disparities in Depressive Symptoms Among Pregnant Women Vary by Income and Neighborhood Poverty. In: AIMS Public Health 2 (2015), pp. 411–425.

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[3] Bijaya K. Padhi, Kelly K. Baker, Ambarish Dutta, Oliver Cumming, Matthew C. Freeman, Radhanatha Satpathy, Bhabani S. Das, Pinaki Panigrahi: Risk of Adverse Pregnancy Outcomes among Women Practicing Poor Sanitation in Rural India: A Population-Based Prospective Cohort Study. In: PLoS Medicine 12 (2015), https://doi.org/10.1371/journal.pmed.1001851.

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[5] Josephine Borghi, Kate Ramsey, August Kuwawenaruwa, Jitihada Baraka, Edith Patouillard, Ben Bellows, Peter Binyaruka, Fatuma Manzi: Protocol for the evaluation of a free health insurance card scheme for poor pregnant women in Mbeya region in Tanzania: a controlled-before and after study. In: BMC Health Services Research 15 (2015), https://doi.org/10.1186/s12913-015-0905-1.

[6] Sarah K. Garwood, Lara Gerassi, Melissa Jonson-Reid, Katie Plax, Brett Drake:

searched and presented by the American authors of general medicine[7]. In 2016, the topics were published on: the impact of poverty on the weight of pregnant women and foetal growth. The American authors, experts in the field of public health, epidemiology, from the Department of Health and Nutrition Sciences, the Centre for Research on Healthcare, and the Departments of Obstetrics, Gynaecology and Reproductive Sciences researched the topic[8]; a similar topic, only with the sign of obesity in African American pregnant women, has been explored by the American scientists in the fields of public health, nursing, epidemiology and of the division of sleep disorders[9]. In 2017, paediatricians, psychiatrists, psychologists, and public health researchers published a paper on how and to what extent nutrition of poor pregnant women affects the cognitive development of a child.[10] In 2018, the interest of scientists was focused on the following topics: perinatal and neonatal pregnancy outcomes in a low-income environment. This topic was jointly explored by the English researchers in the fields of reproductive health, infectious diseases, epidemiology and healthcare, and a scientist from the Malawi University of Science and Technology[11]; the other topic in this year linked poverty to preterm birth and cognitive development of a baby. The epidemiologists, representatives of the behavioural sciences and health education, all

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More than Poverty: The Effect of Child Abuse and Neglect on Teen Pregnancy Risk. In: Journal of Adolescent Health 57 (2015), pp. 164–168.

[7] Rita Hamad, David H. Rehkopf: Poverty, Pregnancy, and Birth Outcomes: A Study of the Earned Income Tax Credit. In: Paediatric and Perinatal Epidemiology 29 (2015), pp. 444–452.

[8] Dara D. Mendez, Roland J. Thorpe, Ndidi Amutah, Esa M. Davis, Renee E. Walker, Theresa Chapple-McGruder, Lisa Bodnar: Neighborhood racial composition and poverty in association with pre-pregnancy weight and gestational weight gain. In: SSM – Population Health 2 (2016), pp. 692–699.

[9] Andrea E. Cassidy-Bushrow, Rosalind M. Peters, Charlotte Burmeister, Lawrence F. Bielak, Dayna A. Johnson: Neighborhood-Level Poverty at Menarche and Prepregnancy Obesity in African-American Women. In: Journal of Pregnancy Volume 2016, https://doi.org/10.1155/2016/4769121.

[10] Betty R. Vohr, Elysia Poggi Davis, Christine A. Wanke, Nancy F. Krebs: Neurodevelopment: The Impact of Nutrition and Inflammation During Preconception and Pregnancy in Low-Resource Settings. In: Pediatrics 139 Suppl. 1 (2017), pp. 38–49.

[11] Jennifer A. Hall, Geraldine Barrett, Andrew Copas, Tambosi Phiri, Address Malata, Judith Stephenson: Reassessing pregnancy intention and its relation to maternal, perinatal and neonatal outcomes in a low-income setting: A cohort study. In: PLoS One 13 (2018), https://doi.org/10.1371/journal.pone.0205487.

from the USA, examined the topic.[12] In 2019, pregnancy outcomes, health and life of newborns were connected by four contents. In order: the American scientists in the field of population health sciences published a paper on different conditions of poverty in urban-rural areas and mortality of infants and children living in poverty[13]; a retrospective study on the impact of poverty on infant mortality from 2000 to 2017 was published in co-authorship by English researchers in the field of public health and policy, from the School of Geography, and the Institute of Health and Society, together with an epidemiologist from Denmark[14]; an article on insomnia, short-term sleep in pregnancy associated with disparities related to poverty was co-authored by the American scientists in the field of sleep disorders, obstetrics and gynaecology, psychiatry, and neurology, and an Italian author in the field of neuroscience and psychiatry[15]; the American paediatricians of general and behavioural paediatrics investigated insecurity of nutrition during pregnancy and breastfeeding in low-income mothers of Hispanic descent[16]. In 2020, the interest of American medical scientists, gynaecologists and psychologists, was focused on the interaction between poverty and cardio-metabolic disorders, and the postpartum cardio-metabolic risk was questioned in different racial/ethnic groups.[17]

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[16] Rachel S. Gross, Alan L. Mendelsohn, Mayela M. Arana, Mary Jo Messito: Food Insecurity During Pregnancy and Breastfeeding by Low-Income Hispanic Mothers. In: Pediatrics 143 (2019), https://doi.org/10.1542/peds.2018-4113.

[17] Kharah M. Ross, Christine Guardino, Christine Dunkel Schetter, Calvin J. Hobel: Interactions between race/ethnicity, poverty status, and pregnancy cardio-metabolic

After presenting the contents that linked poverty, pregnancy, the health of pregnant women, newborns, and infants, which were researched in the field of biomedicine and healthcare, we emphasise the key results obtained by researchers, which unequivocally prove the thesis stated in the title that pregnant women and newborns are particularly vulnerable groups in conditions of poverty. The results show that care for the health of pregnant women, future mothers, and newborns should begin in girls before the onset of their first menstrual period (menarche). Living in poverty during that time can significantly affect the reproductive health of the future pregnant woman. Juvenile pregnancies related to poverty often result in the abuse and neglect of newborns, phenomena to which juvenile pregnant women themselves were exposed during childhood. Additionally, particular attention should be paid to the sanitary conditions in which poor pregnant women live because poor sanitary conditions can affect childbirth outcomes and safe motherhood. Furthermore, it is evident that depression is more common in pregnant women living in medium- or low-poverty environment/neighbourhoods. Prejudice about maternal nutrition during pregnancy, according to which a pregnant woman should be eating for two, raises the risk of obesity more in poor pregnant women than in those who are not poor. Malnutrition in a pregnant woman as a consequence of poverty affects the physical and mental health of the pregnant woman and the foetus, often resulting in preterm infants or infants with restricted growth. In the later period of a child's development in childhood and adolescence, as a consequence of malnutrition, psychological diagnoses, attention deficit, hyperactivity, anxiety, and depression may appear. Children born prematurely or in an earlier period have a tendency to achieve lower cognitive assessments in comparison to full-term children. Cognitive assessments were also lower in children born into a poor environment/family. Furthermore, infant mortality is directly related to the growing rate of poverty. It has been estimated that the increase in infant mortality in England between 2014 and 2017 was linked to an increase in child poverty, and it is suggested that about a third of the increase in infant mortality in that period could be attributed to an increase in poor children. Additionally, poverty causes insomnia, sleep problems, and nightmares. Poor maternal nutrition, i. e. insecur-

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disorders and maternal postpartum cardio-metabolic risk. In: Ethnicity & Health 25 (2020), pp. 1145–1160.

ity in the food availability with high levels of stress in mother, reduces breastfeeding time and limits the healthy diet of newborns and infants. Pregnancy planning, especially in conditions of poverty, significantly affects the health of a pregnant woman, the foetus, and later, the mother, the newborn, and the infant. This is an opportunity in which low-income families can plan the pregnancy to provide the necessary conditions for the pregnancy outcome, and within the appropriate services, obtain timely assistance. Also, mothers from low-income families have shorter maternity leave and stay shorter at home with a child. They return to work earlier due to earnings and full salary. It should be added that employed single mothers earn significantly lower incomes than single fathers. And finally, health systems, policymakers and political officials should take into account that income levels significantly affect the health of pregnant women and newborns, and accordingly provide measures to address the causes that threaten the health of pregnant women and newborns.

Two conclusions can be drawn from the above: 1. medical scientists and practitioners have very clearly highlighted the health issues caused by the conditions of poverty that affect pregnant women, newborns, infants, and mothers, and 2. pointed out that poverty is an issue that transcends the boundaries of medicine and requires the inclusion of sciences and professions that deal with this issue. This was the reason to direct further research on the impact of poverty on pregnancy, breastfeeding, newborns survival, and maternal health to the social sciences and humanities, and among their scientists and practitioners to find solutions for the problems highlighted by scientists and practitioners in the field of biomedicine and healthcare.

3. Pregnancy and poverty in socio-humanistic perspectives

The following part of the article will present and analyse the results of a study of articles published in the Journal of Poverty that also in the past five years in their titles linked the word *poverty* with at least one of the following words: pregnancy, pregnant woman, breastfeeding, newborns, and infants. Since this is a journal that also publishes research in the field of health, the intention was to find and actualise those articles that explore the socio-humanistic aspects of the relationship and impact of poverty on pregnancy, breastfeeding, health, and development of newborns. In the study period from 2015 to 2020, two studies were found. The first is from 2017, in which an American anthropologist actualises and problematises the effect that federal-state policy achieves by promoting breastfeeding and practical responses of women in Southern Indiana to that policy.[18] The second is from 2018, in which American authors from the Faculty of Public Health and the Faculty of Social Work present and analyse critical views on breastfeeding of African-American women living in poverty.[19] The first study does not emphasise the problem of poverty. However, it is significant in that it requires the inclusion of health policy in the design of programs to promote and support mothers who want to breastfeed their children. The second study clearly shows the link between poverty and breastfeeding. The study examined the attitudes and experiences of African American women about breastfeeding while living in conditions of poverty. The sample included African American women because, according to the authors, they breastfeed for a shorter period of time due to poverty and rarely continue breastfeeding after six months to one year of a child's age, despite the recommendations of the American Academy of Paediatrics. Consequently, infants of these mothers have an increased risk of health impairment and twice the risk of mortality compared to infants from other ethnic populations. Although the largest number of surveyed women expressed positive attitudes towards breastfeeding, the authors indicate that this knowledge should also be considered and analysed, taking into account the obstacles that African American breastfeeding mothers face. The first obstacle to breastfeeding, according to the article, needs to be sought and addressed, starting with the historical facts about the unethical relationship to African American women, who were participants in medical research. The authors especially point out the problems of undergoing operative gynaecological procedures without anaesthetics, forced sterilisation that was performed until the 1980s, and the compulsion of African American female slaves to breastfeed their masters' children to the detriment of their own children. To this historical-ethical context that influences building of trust in medicine and medical recommen-

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[18] Rebecca M. Bedwell: The Impact of Federal Breastfeeding Policy Initiatives on Women's Breastfeeding Practices and Attitudes in Southern Indiana. In: Journal of Poverty 21 (2017), pp. 508–527.

[19] Rebecca Reno, Sheila Barnhart, Patricia Temple Gabbe: A Critical Inquiry of Breastfeeding Attitudes, Barriers, and Experiences of African American Women Living in Poverty. In: Journal of Poverty 22 (2018), pp. 518–536.

dations should also be added poverty, which, as the above research results prove, is an essential and unavoidable factor that impairs the health of pregnant women and the survival of newborns and infants. The second obstacle is that African American women believe less than other women that breastfeeding meets an infant's nutritional needs. Furthermore, the third obstacle is defined by poverty since the breastfeeding rate is significantly lower among poor women and women from low-income families. These obstacles clearly indicate that when designing interventions that would contribute to an increased breastfeeding rate, it is essential to take into account the overall socio-cultural context in which pregnant women, mothers and infants live. Taking this context into account could serve as a starting point for understanding the reasons why poverty affects the health and lives of pregnant women, newborns, and infants. On the other hand, once awareness is made that poverty is a clear and identifiable cause of health problems, medical and health professionals can approach the conceptualisation and provision of professional and ethical care to pregnant women, newborns, and infants that poverty identifies as a vulnerable group of patients.

4. Conclusion

Poverty is one of the most topical issues faced by patients, health professionals and scientists in the field of biomedicine and healthcare. This article exposes poverty as an environment within which and under the pressure of which, health professionals perform their daily activities in the processes of treatment and healthcare. From the presented results of the research on the impact of poverty on the health of pregnant women, life and health of newborns and infants, it can be concluded that this is a topic and issue whose research results, on a theoretical level, contribute to mobilising scientific and other potentials to tackle the issues relating to the interdependence of poverty and health of pregnant women, newborns, and infants. Furthermore, by using methodological approaches, measures can be devised to reduce the impact of poverty on their health. On a practical level, this article can serve as a guide to the following scientific, professional, and social fields: 1. biomedicine and healthcare, for constant critical questioning of the importance of an interdisciplinary approach in addressing the relationship between poverty and health, and especially the impact of poverty on the creation of a new vulnerable group of patients. Likewise, the results can motivate health professionals to familiarise health officials and policymakers with the extent to which poverty affects the fact that maintaining and protecting the health of pregnant women and newborns depends on the financial situation and the subordinate level of available funds of the health institution. The article can also serve as a proof to health professionals and patients that, in conditions of poverty, the professional and ethical duties of health professionals, in addition to taking care of the most favourable healthcare options, are also focused on the individual abilities of health professionals to find ways to guarantee everyone, and in this particular case pregnant women, newborns, and infants, the right to health and appropriate medical care; 2. in health policy, this article may encourage the creation of measures and policy interventions whose implementation and application in the practice would reduce poverty as a cause of health and life problems for pregnant women, newborns, and infants; 3. in education, due to the planning and implementation of the issue of poverty and health in the curriculum of medical and health faculties to enable students to adequately and creatively address the challenges posed by the impact of poverty on the formation of new vulnerable groups of patients.

Maja Ebert Moltara, Lučka Boltežar, Maja Ivanetič Pantar, Marjana Bernot

Palliative care – the needs of patients with incurable illnesses and their relatives

Abstract

Background: Palliative care improves the quality of life of patients facing life-threatening diseases and offers support to their caregivers. It must be delivered depending on individual needs of all involved.

Methods: We have collected data on all the patients with incurable cancer who received help from any service of an Acute palliative care department (APCD) at Oncology institute Ljubljana OIL since its beginnings in 2007 up to 2018, retrospectively. Among all of them, we compared palliative care needs according to their age group based on group discussions and experiences of APCD team members.

Results: Among 2698 patients, there were 94 (3.5 %) young (age 15–40 years), 1086 (40.3 %) middle age (41–64 years), 791 (29.3 %) young old (65–74 years), 615 (22.8 %) middle old (75–84 years) and 112 (4.2 %) very old ($\geq$85 years) adults. Palliative care patients have many general needs (physical, psychosocial, spiritual), but in each age-group there can be some additional specific needs according to their diagnosis, concomitant diseases and psychological and social background.

Conclusions: Early identification and assessment of specific age-related palliative care needs are necessary as well as timely and efficient support of them.

1. Introduction

There is a sentence no one wants to hear, »You have cancer«, and we would do anything to avoid it. But the reality is that in 2018 alone, there were more than 18 million new cases of cancer worldwide. With 9.6 million deaths in the same year, it is the second leading cause of death in the world.[1] For all those reasons, cancer represents a physical,

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[1] Freddie Bray, Jacques Ferlay, Isabelle Soerjomataram, Rebecca L. Siegel, Lindsey A.

emotional and financial burden to individuals, families, communities and health systems.

Palliative care is a medical discipline specialised in providing support and care to the seriously ill.[2] According to the WHO definition, it is an approach that improves the quality of life of patients and their families through prevention and relief of suffering by early identification, assessment and treatment of physical, psychosocial and spiritual problems.[3] The multidimensional care of patients' and their relatives' needs can be addressed by good teamwork of interdisciplinary palliative care teams. In oncology, early integrated palliative care (early palliative care) together with other specific therapies (chemotherapy, radiotherapy, surgery) proved to prolong life and positively influence the course of illness.[4]

Palliative care affirms life and accepts dying as a normal and natural process. It intends neither to hasten nor postpone death. It offers a support system to help patients live as actively as possible until death. The main purpose is to preserve the individuals' values and dignity. Access to palliative care is a legal obligation for every country and acknowledged by United Nations conventions as a human right.[5]

There are great disparities between countries in the capacity, resources and infrastructure devoted to the care of people with serious and incurable illnesses.

Annually in Slovenia, we have more than 15,000 new cancer diagnoses, and approximately 6,000 people die from cancer.[6] All aspects of human beings are influenced by the burdens of a cancer diagnosis,

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Torre, Ahmedin Jemal: Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. In: CA – A Cancer Journal for Clinicians 68 (2018), pp. 394–424.

[2] Lukas Radbruch, Liliana De Lima, Felicia Knaul, Roberto Wenk, Zipporah Ali, Sushma Bhatnaghar, et al.: Redefining Palliative Care. A New Consensus-Based Definition. In: Journal of Pain and Symptom Management 60 (2020), pp. 754–765.

[3] World Health Organization: National Cancer Control Programmes. Policies and managerial guidelines. 2nd Edition. Geneva 2002.

[4] Jennifer S. Temel, Joseph A. Greer, Alona Muzikansky, Emily R Gallagher, Sonal Admane, Vicki A. Jackson, Constance M. Dahlin, Craig D. Blinderman, Juliet Jacobsen, William F. Pirl, J. Andrew Billings, Thomas J. Lynch: Early palliative care for patients with metastatic non-small-cell lung cancer. In: The New England Journal of Medicine 363 (2010), pp. 733–742.

[5] Frank Brennan: Palliative Care as an International Human Right. In: Journal of Pain and Symptom Management 33 (2007), pp. 494–499.

[6] Institute of Oncology Ljubljana: Cancer in Slovenia 2017. Epidemiology and Cancer Registry, Cancer Registry of Republic of Slovenia. Ljubljana 2020.

therefore patients as well as their caregivers have additional physical, psychological, social and spiritual needs. Coping with these new life-situations has to be addressed in all affected. This become even more important when the disease progresses to the incurable state, raising several complex issues around mortality. The comprehensive approach of palliative care intends to support patients in this period and provide alleviation of suffering.

In Slovenia, cancer patients are treated by specific oncology treatment in two major cancers centres and in a few smaller clinics around the country. At the same time, patients with incurable cancer receive palliative care from all health professionals at different levels of the medical system: palliative approach, general palliative and specialised palliative care.[7]

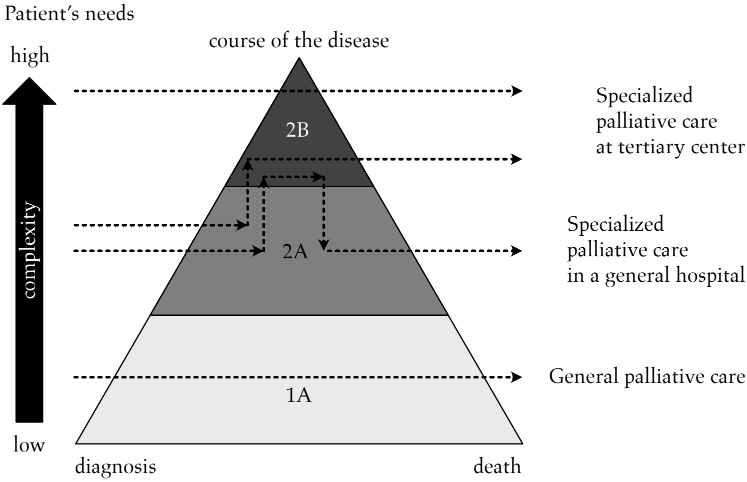

Figure 1: Transition of patients' palliative care needs over period of the progression of a disease

The needs of palliative care patients with cancer change during the course of the disease. They can be simple, where general palliative can handle most of the problems. But sometimes the needs can be extremely complex, where several specialised services and medical professionals need to be included. Most commonly, we see patients

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[7] National Cancer Control Programme: The Slovene NCCP. http://www.dpor.si/eng/# (accessed 3. 10. 2020).

traveling through the medical system according to their needs at a certain point in time.

At the Oncology Institute of Ljubljana, we established a specialised unit for palliative care – Acute Palliative Care Department (APCD) – in 2007. At the beginning, it served only as in-hospital care for palliative care patients; today, the range of specialised activities of APCD is much broader and includes inpatient, outpatient and consultation services and an educational and research centre for palliative care.[8]

The team at APCD is made up of physicians and nurses working together with psychologists, physiotherapist, dietitians, social workers and theologians, all with specialised knowledge in palliative care. With an interdisciplinary approach, they support palliative care patients with complex needs. When those patients are discharged from hospital, general teams at the primary level of the health system take over. The general palliative care team consists of a family doctor and community nurse. Cooperation between specialised and general palliative teams is crucial to enable a comprehensive palliative approach.

2. Methods

In a retrospective study, we reviewed charts of patients referred by their attending physicians to the specialised palliative care service at APCD at the Oncology Institute of Ljubljana between 2007–2018. The range of services provided were different between distinct periods: between 2007–2012, only in-hospital care, from 2013 on, there were additional services included (outpatient, consultation services).

All data, such as patient demographics (age, gender), type of cancer, palliative care services and clinical course, were obtained from archived patient medical records at the Oncology Institute of Ljubljana and from the Cancer Registry of the Republic of Slovenia. According to their age, we divided them into several cohorts as young (age 15–40 years), middle age (41–64 years) and elderly ($\geq$65). The last group we further divided into young old (65–74 years), middle old (75–84 years) and very old ($\geq$85 years) adults.

Among team members of APCD, we conducted interactive directed discussions and exchange of experiences about age-related differ-

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[8] Onkološki inštitut Ljubljana. https://www.onko-i.si/eng/ (accessed 3.10.2020).

ences in the palliative care needs (physical, psychological, social, spiritual).

The major goal of this analysis was to collect general and some specific palliative care needs of patients, as influenced by age. The results were planned to provide the basis and insight into topics that palliative care research needs to focus on in a future.

Categorical data are described using absolute numbers and percentages, continuous by mean, minimum and maximum. The qualitative data analysis was performed using SPSS software, version 22.0.

3. Results

In a twelve-year time period, there were 2698 patients with cancer included in any kind of APCD service (in-hospital, outpatient, consultation). Only 94 (3.5 %) patients were younger than 40 years, 1086 (40.3 %) patients belonged to the middle-aged group between 41–64 years and 1518 (56.2 %) belonged to the elderly group of 65 years or more.

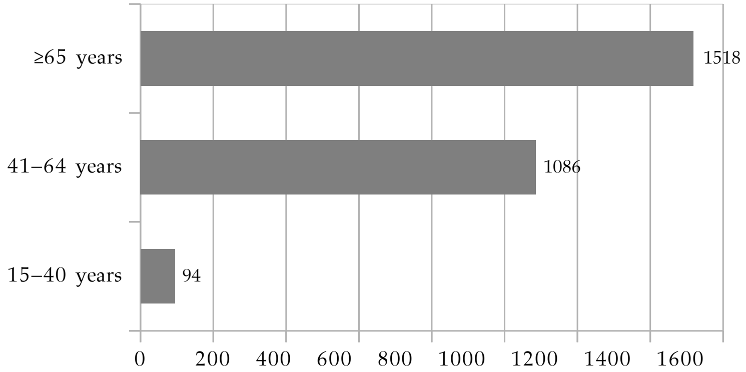

Figure 2: Number of palliative care patients at APCD according to age group between 2007–2018

In a group of elderly there were 791 (29.3 % of all) young old (65–74 years), 615 (22.8 % of all) middle old (75–84 years) and 112 (4.2 % of all) very old (≥85 years) adults.

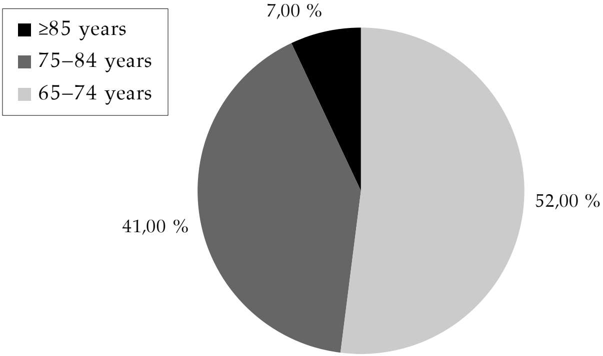

Figure 3: Age distribution only among of elderly APCD patients

The vast majority of all APCD patients were consulted or treated only one time. Regardless of age, the majority were cared for in a hospital department. Compared to others, young patients were more often consulted while being hospitalised in other departments of the Oncology Institute of Ljubljana. Very old patients were more often consulted in an outpatient setting.

With the help of a pre-planned questionnaire and later on in a group discussion of APCD team members, we agreed that all palliative care patients have needs in all four parts of the human being, i. e. physical, psychological, social and spiritual. General needs are common to the majority, but many patients also have some very specific needs. Among them are some age-related, and some depend on other characteristics such as basic diagnosis, concomitant diseases and psychological and social background.

The group of young adults (15–40 years old) generally included patients who were healthy before the diagnosis of incurable cancer. At time of diagnosis, they were usually in good physical condition, with stable nutritional status, that deteriorated only later on during disease progression. Shortly after diagnosis, we could observe psychological problems, some of which can be very individual. A very special characteristic of this group of patients is that they usually have very little experience about death and dying. The most important topics for them are how to cope with insecurity, self-esteem, disruption of body-image, peer-relations, fear and family reactions. Among very special needs are topics of young families, especially those with small children, with questions regarding how to support children and a spouse. A major influence on the psychological wellbeing of such young families depends on support from the broader structure and caregivers such as grandparents and siblings. In regard to special social needs, there is the situation where young people lack financial independence. In regard to spiritual needs, young patients face the complete spectrum of questions about themselves and their loved ones as well as wishing to have control over their lives.

The middle-aged group (41–64 years old) usually included patients with rare co-morbidities, at the beginning in good physical condition, and only later on with the progression of the disease their nutritional status deteriorates. Among them, we observed diverse individual reactions: some with difficult coping with their diagnosis, denial, others with difficulties accepting the loss of body control, especially when the disease progressed quickly. They usually struggle with questions of how to support their own families, wishing »not to be the burden«, fearing for the future of their children, making plans for them. Some patients can be burdened in regard to their legacies. There are individual attitudes towards death and dying that can sometimes be modest and for that reason also troublesome.

Most people in the elderly group (65 and older) have at least some co-morbidities or at least frailty. Symptoms such as dizziness, imbalance, issues of mobility, deafness and poor vision are common. Already during the diagnosis of incurable cancer in the elderly, some nutrient needs may be reduced, but some requirements of essential nutrients may in fact increase, especially with cancer; later on, we can expect nutritional deterioration. Usually, they are more emotionally stable, focusing on the good things in life but still facing new challenges in life that can also produce more anxiety about their safety, depression, feelings of loneliness and isolation. Issues about death and dying are usually influenced by experiences about death and dying with close friends and family. Also, in this group it is very important to care for not isolating from others, to continue socialising, meeting with peers, give a patient opportunity to tell loved ones what they need without hurting them and strengthening contacts with people they don′t know but who can help during this period. An important challenge is also how to arrange the need for basic personal care when there are no healthy family carers. It is very important to respect patient experiences, values, decisions and spiritual support needs (to follow the customs of a patients′ religion and beliefs).

A discussion among APCD team members exposed the importance of the individuality of every single patient. We all agreed that every patient is a person with their own history and their own personal experiences, attitudes toward life and wishes, and that we need to consider them as much as possible in preparing a palliative care plan. We anticipate general and specific needs based on our knowledge and experience, but at the same time we need to stay open to some unique and new aspects that can emerge.

4. Discussion

Palliative care needs to address four basic aspects of the human being: physical, psychological, social and spiritual. Every patient has unique palliative care needs, most of them general, but some can be specific, related to age or other patent characteristics. To provide holistic management of all palliative care needs, patients and their caregivers must be offered a range of different interventions such as symptom management, discussion about prognosis, ongoing specific treatments and diagnostic interventions, actively involving them in discharge planning, counselling about goals of care, patient and caregiver support (including spiritual needs) and discussion about patient values and wishes (advance directives: resuscitation status, completion of a living will).

When an individual palliative care plan is being structured, we have to acknowledge personal characteristics, experiences, values and wishes, but at the same time, we have to anticipate patient needs, both general and also some specific. Some anticipated needs can evolve due to specifics of a disease itself, like prevalence and intensity of symptoms (dyspnoea in COPD, lung cancer) and more frequent neuropsychiatric challenges (in elderly), or other characteristics of patients, like social needs (in elderly, young) and distinct spiritual, religious, cultural needs.

Age of a patient strongly influences care decisions and outcomes, in oncology in general as well as in palliative care.[9] Numerous studies

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[9] John D. Parr, Baohui Zhang, Matthew E. Nilsson, Alexi Wright, Tracy Balboni, Edmund Duthie, Elizabeth Paulk, Holly G. Prigerson: The Influence of Age on the Likelihood of Receiving End-of-Life Care Consistent with Patient Treatment Preferences. In: Journal of Palliative Medicine 13 (2010), pp. 719–726.

studied age as a covariate among the several palliative care decisions and actions, but many topics are still unanswered. Older patients seem to receive less aggressive care but have more discussions about care decisions. In contrast, younger cancer patients have more aggressive treatments and are less likely to be involved in care decision-making.[10] The study of Rose et al. showed that younger patients had longer stays, higher hospital costs and greater probability of rehospitalisation. Fewer older patients preferred CPR or life-prolonging treatments.[11]

4.1 Physical symptoms

A number of studies have shown that there are age-related differences in reporting symptoms such as pain and others among patients with incurable cancer. Some studies noted that older patients were less likely to present with pain.[12] Morita et al.[13] reported that older patients were less likely to present with nausea and vomiting. But Smith et al.[14] and Nugent et al.[15] observed that older lung cancer patients reported more severe dyspnoea than younger patients. Simi-

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[10] Julia Hunnum Rose, Elizabeth E. O'Toole, Neal V. Dawson, Charles Thomas, Alfred F. Connors, Neil S. Wenger, Russell S. Phillips, Mary B. Hamel, Harvey J. Cohen, Joanne Lynn: Age differences in care practices and outcomes for hospitalized patients with cancer. In: Journal of the American Geriatrics Society 48 Suppl. 5 (2000), pp. 25–32.

[11] Julia Hannum Rose, Elizabeth E. O'Toole, Neal V. Dawson, Renee Lawrence, Diana Gurley, Charles Thomas Mary B. Hamel, Harvey J. Cohen: Perspectives, Preferences, Care Practices, and Outcomes Among Older and Middle-Aged Patients With Late-Stage Cancer. In: Journal of Clinical Oncology 22 (2004), pp. 4907–4917.

[12] Sebastiano Mercadante, Gabriella Dardanoni, Leonardo Salvaggio, Maria G. Armata, Antonio Agnello: Monitoring of opioid therapy in advanced cancer pain patients. In: Journal of Pain and Symptom Management 13 (1997), pp. 204–212.

[13] Tatsuya Morita, Junichi Tsunoda, Satoshi Inoue, Satoshi Chihara, Toshihiro Ichiki: Symptom prevalence and risk factors in terminally ill cancer patients. In: Japan Journal of Cancer Clinics 44 (1998), pp. 879–884.

[14] Ellen L. Smith, Danette M. Hann, Tim A. Ahles, Charlotte T. Furstenberg, Tara A. Mitchell, Louise Meyer, L. Herbert Maurer, James Rigas, Susan Hammond: Dyspnea, anxiety, body consciousness, and quality of life in patients with lung cancer. In: Journal of Pain and Symptom Management 21 (2001), pp. 323–329.

[15] William C. Nugent, Mark T. Edney, Paul G. Hammerness, Bradley J. Dain, L. Herbert Maurer, James R. Rigas: Nonsmall cell lung cancer at the extremes of age: impact on diagnosis and treatment. In: The Annals of Thoracic Surgery 63 (1997), pp. 193–197.

lar results were collected in a study by Evers at al.[16] where patients older than 80 needed fewer interventions for pain, nausea, anxiety and other symptoms than younger patients, but more interventions for dyspnoea. But not all of the studies are uniform. As an example, the Hirakawa et al.[17] study, where researchers also compared younger and elderly patients, reported no difference between symptom experience and care receipt.

4.2 Psychological symptoms

The psychological implications of incurable cancer result in a range of challenges for both the patient and the caregivers. Patients and caregivers may experience feelings of fear, being a burden to others, loss of control, anger, loss of sense of dignity and uncertainty, or they present with symptoms such as an anxiety, distress and depressive episodes. Uncontrollable pain and intense unrelieved physical symptoms can sometimes even deepen the feelings of helplessness and hopelessness. Caregivers have an important and challenging role in this matter, providing emotional and social support for the patient, helping with medical needs and meeting increasingly complex instrumental needs such as running the household and work.[18]

There are some obvious differences in psychological needs between certain age groups.[19] Younger patients with incurable cancer have unique psychosocial needs that besides coping with this serious

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[16] Martin M. Evers, Diane E. Meier, R. Sean Morrison: Assessing Differences in Care Needs and Service Utilization in Geriatric Palliative Care Patients. In: Journal of Pain and Symptom Management 23 (2002), pp. 424–432.

[17] Yoshihisa Hirakawa, Yuichiro Masuda, Masafumi Kuzuya, Akihisa Iguchi, Kazumasa Uemura: Age-related differences in care receipt and symptom experience of elderly cancer patients dying at home: Lessons from the DEATH project. In: Geriatrics and Gerontology International 7 (2007), pp. 34–40.

[18] Louise Burzotta, Helen Noble: Providing psychological support for adults living with cancer. In: End of Life Journal 4 (2010), pp. 9–16; Amy S. Kelley, R. Sean Morrison: Palliative Care for the Seriously Ill. In: The New England Journal of Medicine 373 (2015), pp. 747–755; Betty R. Ferrell, Martha L. Twaddle, Amy Melnick, Diane E. Meier: National consensus project clinical practice guidelines for quality palliative care guidelines. In: Journal of Palliative Medicine 21 (2018), pp. 1684–1689.

[19] Sharyl J. Nass, Lynda K. Beaupin, Wendy Demark-Wahnefried, Karen Fasciano, Patricia A. Ganz, Brandon Hayes-Lattin, Melissa M. Hudson, Brenda Nevidjon, Kevin C. Oeffinger, Ruth Rechis, Lisa C. Richardson, Nita L. Seibel, Ashley W. Smith: Identifying and addressing the needs of adolescents and young adults with cancer:

disease, encompass turning points in their physical and mental development such as changes in identity, body image, sexuality, professional and personal goals, obstacles in relationships with others and sometimes also with young parenthood.[20] Feelings such as uncertainty, vulnerability, loss of control, anger and isolation are common. Some patients and relatives may even hesitate to talk openly about the incurable state of disease and death, but experience tells us that in the young group of patients, there is need for discussion about those topics.[21] Addressing their fears, preferences and wishes usually relieves the stress and helps them in coping with the situation. Some evidence even suggests that in this group »(…) palliative care is not only needed, but it is critically beneficial to patients, families, and healthcare professionals alike.«[22]

In the older group, psychological needs are a bit different. We observe emotional symptoms, such as anxiety, loneliness, depression and anger, that someone might acknowledge as a normal reaction. But in the holistic approach of palliative care, psychological symptoms need to be addressed, because that improves the quality of life of patients and helps them in coping with a situation. In a Reynolds et al. study, patients over 55 years of age experienced depression and anxiety in 11.4 % and 6.8 % respectively.[23] Delirium is also extremely prevalent in hospitalised older patients, with an estimated 8–15 % of palliative care patients affected.[24]

Summary of an Institute of Medicine workshop. In: The Oncologist 20 (2015), pp. 186–195.

[20] Abby R. Rosenberg, Joanne Wolfe: Palliative care for adolescents and young adults with cancer. In: Cancer 117 Suppl. 10 (2011), pp. 2323–2328.

[21] Rosenberg, Wolfe: Palliative care for adolescents (Note 0).

[22] Rosenberg, Wolfe: Palliative care for adolescents (Note 0).

[23] Kristin Reynolds, Robert H. Pietrzak, Renée El-Gabalawy, Corey S. Mackenzie, Jitender Sareen: Prevalence of psychiatric disorders in U.S. older adults: findings from a nationally representative survey. In: World Psychiatry 14 (2015), pp. 74–81.

[24] Julia Barnes, Suzanne Kite, Manoj Kumar: The recognition and documentation of delirium in hospital palliative care inpatients. In: Palliative and Supportive Care 8 (2010), pp. 133–136.

4.3 *Social issues*

Care for social issues is part of the everyday tasks of any interdisciplinary palliative care team, but specialised interventions often fall to specific professionals like social workers. The goal of social care interventions is to improve social support, which benefits patients in a variety of ways. Better social engagement in any age group is associated with better subjective wellbeing[25], quality of life[26] and better physical function.[27] In a study by Holt Lunstad et al., older patients who experience subjective social isolation had higher mortality,[28] more depressive symptoms and increased psychosocial distress.[29]

A key feature of family care is support during bereavement adapted to the age-group of a patient. In a young patient, we usually need to support the parents, partners, siblings or sometimes also very young children.

4.4 *Spiritual support*

Spiritual and religious health is an important factor in overall health. There are many proven positive effects of spirituality on a patient's quality of life, no matter the patient's age.[30] For these reasons, it re-

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presents an intrinsic and essential component of palliative care.[31] Delivery of spiritual care is a key role of the interdisciplinary palliative care team.[32]

Spiritual care is an especially important component in the group of elderly patients,[33] where it predicts social support, physical functioning and fewer depressive symptoms, better cognitive function and improved cooperativeness.[34]

5. Conclusion

Today, we document disparities in many areas of healthcare, also in the field of palliative care. Palliative care consists of the active total care of patients with a serious and life-threatening illness and support to their caregivers. It involves an interdisciplinary approach to symptom management, preservation of function and quality of life. Every patient at any stage of serious, especially incurable, disease should receive palliative care, regardless of age, sex, race or other characteristics. No matter when and where we treat such patients, we need to approach them holistically and offer general support for all aspects of the human being (physical, psychological, social, spiritual). Still, we must be aware that some distinct groups of patients at a certain point in time or in a specific situation may require different approaches. Each patient has their own personality, with their own values, beliefs and wishes, and we need to respect that. Only in this way palliative

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care can provide the best quality of life and the dignity of dying for all patients, independent of their characteristics, and sufficient attention to caregiver needs during all phases of a disease, even in the phase of grieving.

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