

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 neo-liberal 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-

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 anywhere 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-

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 Gómez, 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.

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 2017-2021¹¹).

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

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

¹³ Uršula Lipovec Čebren (Ed.): *Kulturne kompetence in zdravstvena oskrba. Priručnik 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 NPUR¹⁴ and publications on the Roma (public) health¹⁵ 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.

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 Nikolič (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 staff 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 publica-

tions.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

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.

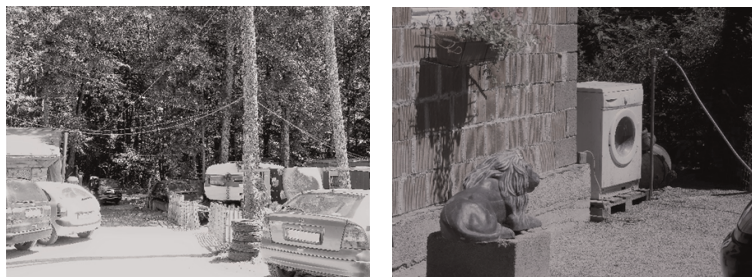
¹⁸ Jože Zadavec: Zdravstvena kultura Romov v Prekmurju [Health culture of Roma in Prekmurje]. Pomurska založba, Murska Sobota 1989.

¹⁹ Duška Knežević Hočvar: 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

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

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

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.

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.

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 breast-feeding«. ³⁴ In their urge to »help« those women they consult about contraception and found rejection from 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

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' 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 anywhere 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

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

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

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

This text is part of the CRP project »Barriers for decent life of members of Roma settlements in the areas defined in the EU Framework for National Roma Integration Strategies up to 2020 (V5-1920)« led by Dr Maša Kovič-Dine, University of Ljubljana, Faculty of Law. Partner: Dr Alenka Janko Spreizer, University of Primorska, Faculty of Humanities, Institute of intercultural studies. This study was a part of a wider project and was not a subject of Ethic Committee.

⁴⁵ International Holocaust Remembrance 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).