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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 in-

creasingly 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

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-

[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

[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.«

[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

[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

[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.

[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.