

Organizational Change in the Sphere of Health Protection of the Roma Community in Poland Seen From Different Perspectives

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Abstract

Purpose: The intent of this study is to get insight into the different views on Roma health in Poland to improve health, access to healthcare and broaden the understanding of the limitations for the Roma inclusion in the mainstream of organizational behaviour of health and well-being institutions.

Design/methodology/approach: The lack of institutional success up to date in the conduct of policies supporting the Roma on the path to an even standard of living, including health, suggests seeking new organizational approaches. To find the answers to these questions “What views do the Roma/Roma experts/Polish society have on Roma health?” qualitative research was done: six semi-structured open-ended interviews were conducted in the Roma community in Ochotnica Górna village in the Carpathian Mountains (across three generations), one structured and two semi-structured open-ended interviews with experts, observations of the living environments of the Roma interviewees and collection of newspaper articles as well as an analysis of different statistical data.

Findings: The main insights that were provided by the views of Roma experts are the differences of approaches to health issues between Roma groups in Poland. The main insights that the newspaper articles give into the views of the society on Roma health are that the denigrating view on the Roma is still present in society, as some statements created a narrative of ‘othering’.

This study also shows the change of views in time, as conformation to Romanipen principles is being relaxed among younger generations so their view on health and health care is changing. The policy in Poland that addresses the health issue of Roma is the National Roma Integration Policy 2014–2020, targeted to the whole Polish Roma population, homogeneously, although the target population is rather heterogeneous. This should be changed in the coming years.

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Research limitations/implications: A serious limitation in the research was the lack of willingness of both of the Roma people and Roma experts to participate in the study, and especially to share their insights on health, the protection of which follows the restrictive tradition of Romanipen. Generally, conducting research only in Ochotnica Górna narrows the scope of this study to one particular village, even if the organizational solution is similar all over Poland.

Originality/value: The value of the obtained results is increased by their uniqueness, as the separate issues of Roma health are not raised in Polish literature.

Keywords: Roma population, health, organizational policy, historical change.

JEL: I310, B590

Zmiana organizacyjna w sferze ochrony zdrowia społeczności Romów w Polsce widziana z różnych perspektyw

Streszczenie

Cel: celem badania jest zapoznanie się z różnymi poglądami na temat zdrowia Romów w Polsce w celu poprawy stanu zdrowia i dostępu do opieki zdrowotnej tej społeczności oraz poszerzenia zrozumienia ograniczeń związanych z włączaniem Romów do głównego nurtu zachowań organizacyjnych instytucji zajmujących się opieką zdrowotną i dobrostanem.

Postępowanie badawcze/metodologia/podejście: brak dotychczasowych sukcesów instytucjonalnych w prowadzeniu polityk wspierających Romów na drodze do wyrównanego poziomu życia, w tym zdrowia, sugeruje poszukiwanie nowych podejść organizacyjnych. W celu zbadania tych różnych poglądów sformułowano odpowiednio główne pytania: jakie poglądy na zdrowie Romów mają sami Romowie/eksperti romscy/spoleczeństwo polskie? Aby na nie odpowiedzieć, przeprowadzono badanie jakościowe: sześć częściowo ustrukturyzowanych wywiadów otwartych zebrano w społeczności romskiej we wsi Ochotnica Górna w Karpatach (w trzech pokoleniach respondentów), jeden ustrukturyzowany i dwa częściowo ustrukturyzowane wywiady otwarte z ekspertami, ponadto obserwacje środowiska życia respondentów romskich oraz przeanalizowano zbiór artykułów prasowych i różne źródła danych statystycznych.

Wyniki: głównymi spostrzeżeniami, dokonanymi na podstawie opinii ekspertów romskich, są różnice w podejściu do kwestii zdrowia między grupami romskimi w Polsce. Spostrzeżenia, jakie artykuły prasowe dają na temat poglądów społeczeństwa polskiego w kwestii zdrowia Romów, to fakt, że poniżające poglądy na temat tej mniejszości są nadal obecne w społeczeństwie, ponieważ niektóre wypowiedzi stworzyły narrację o jej silnej „odmienności”. Badanie to pokazuje nie tylko zróżnicowanie poglądów wśród grup romskich w Polsce, lecz także zmianę tych poglądów w czasie, ponieważ podporządkowanie się zasadom Romanipen coraz mniej dotyczy młodszych pokoleń, a więc zmienia się ich spojrzenie na zdrowie i opiekę zdrowotną. Polityka odnosząca się do kwestii zdrowia Romów w Polsce sformułowana w „Programie integracji społeczności romskiej w Polsce na lata 2014–2020”, jest jednolita, chociaż populacja docelowa jest raczej niejednorodna i skierowana do całej populacji Romów w Polsce. Należałoby to w następnych latach zmienić.

Ograniczenia/implikacje badawcze: poważnym ograniczeniem był brak chęci obywateli romskich do udziału w badaniu, a zwłaszcza do dzielenia się spostrzeżeniami na temat zdrowia, którego ochrona powinna być zgodna z restrykcyjną tradycją Romanipen. Przeprowadzenie badań terenowych tylko we wsi Ochotnica Górna zawęża zakres niniejszego opracowania do jednej konkretnej miejscowości, nawet jeśli rozwiązania organizacyjne w zakresie ochrony zdrowia populacji są podobne w całej Polsce.

Oryginalność/wartość: wartość uzyskanych wyników zwiększa ich unikalność, gdyż problematyka zdrowia Romów, jako osobne zagadnienie, nie jest poruszana w polskiej literaturze.

Słowa kluczowe: Romowie, zdrowie, polityka organizacyjna, historyczna zmiana.

1. Introduction

The Roma are the largest ethnic minority in Europe, and make up 1.2% of the European population, which is around 11 million people. Their number is estimated at 6 million in the Community countries and 4 million in the enlargement region, mainly in the Balkans. The European Commission refers to estimates of the European Council from several years ago and to effective declarative statistics. However, this may be an underestimation for not all the Roma have national documentation or are registered as Roma in fear of stigmatisation (Kucharczyk, 2020). The Roma are originally from northern India, and travelled into Europe from the 11th to the 15th centuries (Guglielmo & Waters, 2005; Parekh & Rose, 2011). From the start, they never assimilated with the communities they settled in, but lived segregated or mobile lives, which often gave rise to conflict (Pogány, 2004). Living a mobile or segregated life is partly to preserve the Romani culture and identity (Hancock, 1999) but also because of the history the Roma have in Europe. Soon after their arrival, they were enslaved and persecuted and in the 18th century in Austria-Hungary children were separated from their parents to be raised in non-Roma families (Hajioff & McKee, 2000). During the 20th century, in the Holocaust (Samudaripen), half a million Roma were killed and during the Czechoslovak regime Roma women were sterilized as part of the governmental policy (Holt, 2005). This hostility all throughout history resulted in the Roma being suspicious of the intentions of non-Roma (local) authorities (World Bank, 2019). The Roma are still subject to discrimination and prejudices, all through history and in all of Europe (Orosz, Buneau, Tropp, Sebestyen, Toth-Kiraly, & Bothe, 2017; Marushiakova & Popov, 2017; Masseria, Mladovsky, & Hernández-Quevedo, 2010; Krumova & Ilieva, 2008). This in turn influences many aspects of their life, including employment, education, access to health services and housing (Puckett, 2005; Földes & Covaci, 2012).

They face barriers to their participation in the labour market on an equal basis, which denies them the opportunity to gain financial, physical and social capital (World Bank, 2019). Therefore, the Roma more often live in poverty than the majority of the population (Parekh & Rose, 2011). On top of this, their returns to education are low and engagement in the labour market is low, which hinders the ability of households to accumulate an income and increase their socioeconomic status (World Bank, 2019).

Many policies and projects have been in place to combat discrimination and to promote integration of the Roma into European communities. But these efforts have been called weak and unsuccessful (Parekh & Rose, 2011) mostly because in policies they are often not regarded as a minority but as immigrants due to their (historically) mobile and segregated lifestyle. This denied them minority rights (Guglielmo & Waters, 2005; European Roma Rights Centre, 2006).

The situation resembles the phenomenon pointed out by Buder (2017) and Vance (2016) in the USA, where for centuries Americans have been convinced of their positive uniqueness or entrepreneurship and at the same time a significant proportion of citizens (regardless of colour) living in the so-called The Rust Belt remains in terrible economic and social conditions. Like the Roma, they are credited with a certain lack of acculturation capacity for new conditions and flexible modernity.

Policies towards the Roma historically were often security-oriented, aiming to control the Roma population, which was viewed as alien and untrustworthy, destabilizing the community. But recently the policies are more shifting to being focused on discrimination and minority rights (Guglielmo & Waters, 2005). This shift took place when the EU expanded and more Eastern and Central European countries entered the EU, which increased the number of Roma living in the EU. An EU strategy on the Roma has existed since 2012. Its creation was aimed at confirming that the EU intends to seriously address the social and economic difficulties of the Roma. The main goal is to improve the situation of the Roma in four areas: providing access to education, to work, to healthcare and to improve the housing situation. In Poland, such a programme has existed since 2004 at the level of the whole country, and in Lesser Poland (Małopolska) even earlier, since 2001. But the result is not impressive (Cianciara, Nowicka, & Sitarek, 2012). In the opinion of Szewczyk (Kucharczyk, 2020), maybe the problem is not the strategy itself but officials and all actors involved.

This refers in some way to the concept of *organizational recall* proposed by Ochowski (2017) based on the previous concept of *organizational oblivion* (Ciuk & Kostera 2010). But in this case, perversely, it is important to remember that earlier, historical institutional approaches to the issue of Roma equality in the economic and social system did not bring positive results. So let us remember what we should no longer keep in the approach and activity of the institution.

2. The Roma in Poland

Poland was one of the countries entering the EU in 2004, which changed the situation for the Roma in the country. Around 30,000 Roma are estimated to be living in Poland, which is 1% of the population (Polish National Integration Strategy, 2014). But due to the mass migration among EU countries, there may be more than half of that group actually living in Poland. In 2011, only 16,723 Polish citizens identified themselves as belonging to the Roma ethnic minority (Polish National Integration Strategy, 2014). Due to their relatively small numbers, the Roma in Poland have not received much attention. But because of Poland's transition to democracy, there has been a change to that, as treatment of minority populations has been recognized to be an indicator of democracy for a country (Puckett,

2005; Grygienc, 2015). During this transition, the economic hardships led to a rise of nationalist sentiments, which made the Roma one of the scapegoats (Puckett, 2005). Poland received criticism on the way the Roma were treated in the country. Issues such as housing and employment are not dealt with properly by the government, as the Roma fall under the Ministry of Culture and Arts in Poland, which results in the assumptions that their problems only have to do with culture preservation (ERRC, 2000). The control by the Supreme Audit Office (NIK) of the implementation of tasks by the municipalities of the Lesser Poland (Małopolska) voivodship under the “Programme for the integration of the Roma community in Poland for the period 2014–2020” has shown that none of the reviewed municipalities have created their own local programme of social integration of the Roma; nevertheless, considerable funds were allocated (NIK, 2017).

Another broader problem is that the percentage of people living in poverty in Poland is not getting lower with time going. This results in the fact that the Roma are often perceived as a competing group for financial assistance, which leads to social conflicts on ethnic grounds (Giza-Poleszczuk, 1992; Polish National Integration Strategy, 2014). This also contributes to a vicious circle as the most important factors influencing marginalisation are poverty, health and wellbeing (Giza, 2015).

There are several different Roma groups living in Poland. The largest group is the Polska Roma, who were, until the 1960s and 1970s, living nomadic lives but are now permanently living scattered all over the central part of Poland. The Bergitka Roma have been sedentary for centuries, they travelled through the Carpathians and settled down in mountain villages in southern Poland in the 18th century. Kelderasha (descendant from boilermakers) and Lovara (descendant of horse hawkers) came from what is now Hungary and Romania in the middle of the 19th century. They are also living scattered across Poland (Malyarchuk, Grzybowski, & Derenko, 2006; Marushiakova & Popov, 2017). There is also a small group of Sinti living in Poland, but they often do not identify themselves as Roma (Polish National Integration Strategy, 2014). Some can see the Roma identity as a historically contingent form framed in history (Kapralski, 2018).

Most of the Polish Roma live in urban areas, although in rural areas in the Lesser Poland, there are also some larger Roma settlements. When Poland entered the EU, a number of Roma migrated to the west of Europe, and at the same time, mainly Romanian and Bulgarian Roma migrated to Poland (Polish National Integration Strategy, 2014).

The EU has an important role in influencing Roma policies in Poland, as there is also an ‘EU framework for national Roma integration strategies up to 2020’, on which the strategy of Poland is based, which aims to: 1. Ensure that all Roma children complete at least primary school; 2. Cut the employment gap between Roma and the rest of the population; 3. Cut

the gap in health status; 4. Cut the gap in access to housing and public utilities (European Commission, 2018).

3. Purpose of the Study and the Methods

“Romany populations provide a series of strange paradoxes to any social theory that wants to think in long-term social, quasi-evolutionary, history – inverting the very puzzle...” (Stewart, 2013, p. 3)

The intent of this study is to get insight into the different views on Roma health in Poland. In the neighbouring countries, health issues in the Roma community were scientifically researched, while in Poland, health is mainly written in the press, and sporadically (Cianciara, Nowicka, & Sitarek, 2012). There are also occasional medical studies on emerging epidemics in the Roma community, such as measles (Orlikova, Rogalska, Kazanowska-Zielinska, Jankowski, Slodzin, & Kess, 2010). Presumably, the reason for the lack of interest in Roma health study is a much lower percentage of the Roma population in Poland compared to analogous proportions in the neighbouring countries. This study is intended to fill this gap at least a bit.

As three different viewpoints will be studied, this research has three purposes. The first purpose of this study is to get insight into the personal experiences and view on health and healthcare of the Roma in Poland as they are the ones who experience the problem. It is important in making effective and appropriate policies to hear the voices of the target population (Bacchi, 2016). Second, the propose of this study is to also get insight into the view of experts on Roma health, as experts are regarded to be important in influencing policies (researchers, government) and helping to realize the policies (NGOs) (Barany, 1998; European Commission, 2018). The third purpose of this study is to get insight into the view of the Polish society on Roma health, as it became apparent from literature that this view has changed over the years in different aspects (Polish National Integration Strategy, 2014; Pogány, 2004; Giza-Poleszczuk, 1992).

In order to investigate these different views on Roma health, the following main research question was formulated:

What insights can looking at different viewpoints give into Roma health in Poland?

And as mentioned before, three different views appeared to be relevant from the literature review, which led to the following sub-questions:

- What views do the Roma have on their own health and what are their experiences with health and healthcare in their lives?
- What views do Roma experts have on Roma health (inequity)?
- What views does the Polish society have on Roma health?

To find answers to these questions, qualitative research was done. Qualitative research gives a more holistic account in reporting on multiple perspectives and it is the most suitable way to give insight into people’s ideas

and experiences (Creswell, 2014; Clandinin & Connelly, 2000). Different data sources were used: interviews with the Roma, interviews with experts, observations of the living environments of the Roma interviewees and newspaper articles. Different methods were used to obtain and analyse these data, which will be explained in detail below.

One of the characteristics of qualitative research is that the participants' meanings are the focus of the research. This study is focussed on learning the meaning of health and healthcare for the participating Roma (Marshall & Rossman, 2011). The researchers asked individuals to share their view on their health and the health of their family members as well as their experiences with healthcare. These data were collected in the participants' natural setting, meaning that they were visited at their homes, 'in the field' at the site where they experience health problems or have experiences under study (Nowicka & Witkowski, 2019; Creswell, 2014). Using open ended questions about their experiences gave the participants the directing role in the conversation and provided the researchers with information the participant thinks is important. The semi-structured open-ended interviews provided the researchers with the context of the data, as the participants shared information about their social, cultural lifestyle (Riessman, 2008).

Non-governmental organizations were described in the literature as important players in the field of Roma health improvement (Brodziński, Borawski, & Dunn, 2017). Therefore, NGO personnel was chosen as an expert group to be interviewed in order to study their view on the issue. Structured interviews were chosen as the best method to collect data from the NGO staff members, as the researchers wanted to know exactly what they do as an organization and if they affiliate with the topic of Roma health and if so, how they approach it.

Furthermore, researchers who are involved in the topics related to Roma health or wellbeing in Poland were selected as an expert group to be interviewed about their insights on the topic and their experiences in their research with the Roma. They were chosen as they are knowledgeable about the topic of Roma wellbeing and culture. Therefore, it would be interesting to have their view as experts on Roma health.

To provide the third viewpoint, three different newspaper articles were analysed to get an insight into the views of society on Roma health as such documents can also be an available source of data to get insight into the views on Roma health (Creswell, 2014).

Collection Procedures

Six semi-structured open-ended interviews were conducted in Ochotnica Górna village in the Carpathian Mountains, Lesser Poland voivodeship, in southern Poland. The small village is populated by both Roma and non-Roma inhabitants (2,100 citizens). The Roma have lived in this area at least since the beginning of the 20th century and have recently started to

identify themselves as Bergitka Roma (Gruber, 2009). The Roma groups settled there because they were skilled blacksmiths and this expertise was needed in this region; they remained involved in blacksmithing until the 1960s (Gruber, 2009).

Two interviews were done with two women on their travel back home. Three other interviews were done with women living in the Roma community in the particular village. And the sixth interview was conducted with a woman sitting on the terrace in the village; she was not of Roma origin herself, but a close neighbour of the community.

The particular village was approached as one of the interviewed experts (expert 2) had done research there herself. This site was selected for interviewing and observations, as the village contains one Roma community that is living there together. In this way, community life could be observed and interviews could be done in their natural setting (Nowicka & Witkowski, 2019; Creswell, 2014; Miles & Huberman, 1994). Because the different generations live together, the Roma of different generations could be interviewed.

The interviews were semi-structured and open-ended as the researchers asked about several themes that were chosen based on subjects that emerged from the literature review as important factors in Roma health. Those themes were the following:

- Personal reflection on health,
- Lifestyle, health of family members,
- Health insurance,
- Employment,
- Visits to public healthcare facilities,
- Cultural view on health,
- Differences between groups in Poland.

Next to the interviews, observations were done to collect data on the living environment of the Roma community. Living environment is an important factor influencing health as an important theme emerging from the literature (World Bank, 2019; Nowicka & Witkowski, 2019; Puckett, 2005). So, observations as well as interviews provided data when studying the Roma's view on health and health experiences. Qualitative observations were made by taking field notes in an unstructured way, recoding the activities at the research site and its physical setting (Creswell, 2014).

To gain insight into the view of experts on Roma health, three experts were interviewed. The experts were two academic scholars who do research on the topic of Roma: a professor at the Pedagogic University in Cracow (expert 1), a professor of social anthropology at the University of Warsaw (expert 2) and a Roma affairs consultant working for the local government of Warsaw (expert 3).

The participants for expert interviews were found through the extended network of the researchers of this study. NGOs were also contacted through

email and phone when contact details were available on their websites. None of the NGO staff members were interviewed, as invitations for interviews were not answered or turned down.

One of the experts (expert 1) was interviewed using a structured interview, through email because of practical reasons. The other scholar was interviewed in person using a semi-structured interview (expert 2). The Roma consultant (expert 3) was interviewed shortly by phone using semi-structured interviewing, as her director extended no permission to do an in-depth interview. The interview questions were tailored to get insight about their view on Roma health inequalities and how their views relate to the different themes based on the literature review that were discussed with the Roma community members as mentioned above.

In order to also get an insight into how the society views Roma health, two newspaper articles were examined, which is a qualified method to get an insight into views (Marshall & Rossman, 2011; Lincoln, Lynham, & Guba, 2011). Newspaper articles were searched on the internet, using the search terms: Roma, Roma communities and settlements, health, healthcare, infectious diseases.

The researchers made all data anonymous, making it impossible to trace back to the participants. Also the researchers made sure to respect the rights, needs, values and desires of the participants by informing the interviewees about the study, the way the interview would be conducted, what the aim of the interview was and that the interviewees always had the possibility to discontinue the interview.

4. Definition of Terms

The following section defines how key terms will be used in this study.

The Roma are an ethnic group. In this study, when the term Roma is used, it refers to the Roma who have been living in Poland for generations, since 15th–16th century, unless otherwise mentioned. It does not speak about the recently migrated Roma from e.g. Romania.

Roma-expert is used in this study to indicate an academic scholar researching the Roma or a person working with the Roma professionally (like a consultant to the NGO staff).

Roma assistant is used in this study to refer to a member of the Roma community, thus being of Roma origin and being the bridge in terms of communication between the public school and the Roma community.

Romanipen consist of a set of Roma beliefs and definitions to structure the universe in “clean” and “unclean” categories – meaning that some things, jobs or people cannot be touched or practiced as they are regarded as unclean.

5. Obstacles

Difficulty was experienced in finding people, both of Roma origin and Roma experts, who were willing to be interviewed on Roma health. To get insight into expert views on Roma health inequity, people working for governmental bodies or NGOs related to Roma empowerment were invited for interviews. Many NGOs were approached by email or phone, yet no answer was received. A reason for this could be, as mentioned by expert 3 during the interview, that these organisations applied for the grant that was available from the EU some time ago. Most of the organizations did not receive funding, so “they are nonexistent now” (expert 3). When the call for proposals came from the EU for Roma projects, many NGOs were set up and responded, so their websites are still available but the organizations are inoperative now. The Roma consultant (expert 3) spoke about the arrangements of these organizations, saying that many people of the Roma community wanted to be part of an organization, “but they all wanted to be the president, not a ‘regular’ employee” (expert3). Two other researchers were contacted but replied as ‘not being interested in the topic’ and one of Roma origin had moved abroad and “didn’t have anything to do with the Roma in Poland anymore”.

6. Results

Trough the contacts of expert 2, who was interviewed, the Roma community was approached and five different women of the same family, across three generations, were interviewed. Two sisters aged approximately 60 years (respondents 1 and 2) were interviewed at the bus station on the way to a mountain village in southern Poland. They were born in that village but moved to another city a few hours away. Two other women, approximately 40 years old (respondents 3 and 4), also sisters, were interviewed in the village at the home of one of them (respondent 3). The 25-year-old daughter-in-law of respondent 3 (respondent 5) walked in and was also briefly interviewed. At a terrace in the village, a non-Roma woman in her seventies was interviewed (respondent 6). She was asked about her experience living closely with the Roma community.

Living Environment

The property of the Roma community that was visited consisted of a four-storey-tall building of about 20 apartments on a stroke of land alongside a stream, parallel to the asphalt road through the village. The ground around the apartment block was dusty and children as well as adults wore worn-out clothes. Two sheepdogs on a leash at the entrance of the property did not appear to be well looked-after. Clothes were hung to dry on a fence around the apartment block and inside it smelled heavily of cigarette smoke.

Around eight men aged 30–50 years were sitting outside on sofas. They were chatting, drinking coffee and smoking. Children, 50 in the community (according to respondent 3), were playing around the block. Women were either inside or walking outside, one with a stroller with small children around her. Teenagers were also hanging around with smaller children.

The flat in which one of the interviews was conducted was very cosy, clean and well developed. Residents were not informed about the visit. The respondents were very nice and hospitable. The refreshment appeared quickly with many nice words. Answers were willingly given.

Community Life and Family

Respondent 3 had seven children, respondent 2 said she had eleven children and mentioned that also “younger generations still have many children, one family member has six daughters and another six sons”. Respondent 4 had at least three children, a son aged nine and a daughter aged five, and a daughter who herself had a baby girl aged three months. Respondent 1 said openly that she and her husband were never able to have children, as she had had an ovary cancer and with “life saving surgery” parts of her reproductive organs had been removed when she was 24 years old.

Expert 1 mentioned that family life is seen as off limits for healthcare intervention. “Both Bergitka Roma and Polska Roma do not let healthcare interfere with sexual and reproductive health, including reproductive rights, contraceptives and women’s sexuality. Those topics are seen as a ‘family matter’.”

Prevalent Diseases

“Mental disabilities were present in all families” (respondent 3). Respondent 3, a woman in her mid forties, said that she had “6 children who are healthy and one who is handicapped”, using the word in the meaning that the child was mentally impaired. Expert 2 also mentioned that intermarriage of the Roma of different groups was “not done” and that was the reason why mental impairment was prevalent among Roma groups in Poland.

Respondent 4, a woman in her late thirties, had also a lower mental capacity herself. She mentioned: “many children have diseases”. Her son aged 9 years suffered from asthma and allergies, and when he was 3 months old, he had something with the muscles in his face, around his eyes, and he needed surgery for that. She also had a granddaughter aged 3 years who was at that moment in a specialized children’s hospital in Warsaw, for kidney failure. Her daughter (the mother of the child) was with her in Warsaw, together with her husband (the grandfather of the child).

From the observation as well as from the verbal affirmation by respondent 1, it appeared that she was obese and she explained that she had cardio-vascular diseases as well as hypertension. She also explained that probably because of the obesity, she was quickly tired and went to bed early

every evening. Her husband was more obese than she was, she narrated, and also suffered from a kidney disease, he had been in hospital “many times”.

From the observation in the Roma village, it appeared that the majority of the several 30–50-year-old men who were sitting outside on couches, drinking coffee and chatting, were obese. “Most men above 40 suffer from cardiovascular diseases” and “the husband of a female neighbour has recently had a heart operation, to place stands”. Also, her sister’s husband has recently had a heart attack and had to go “to many hospitals” (respondent 3). This is also consistent with the test results of Cianciara, Nowicka & Sitarek (2012).

Respondents 1 and 2 were sisters and spoke about their parents; their mother had also suffered from many diseases, including a kidney disease, and died at 75. Their father had reached a respectable age of 96 despite “drinking a lot of alcohol” and having a car accident, which left him with the inability to move his left leg and right hand. He “was not used to going to hospital” but had to go because he needed rehabilitation after the accident.

When later asking respondents 3 and 4 about accidents, they did not want to go into more details as to say that they happened often. This may be related to the fact that “some nights the men are drunk” as said respondent 6, a non-Roma village woman having Roma neighbours. She “has no problems with” this, apart from when “the men are drunk at night and the women have to throw out cold water to stop them fight”.

Habits in Using Healthcare

Nonetheless, Bergitka Roma women spoke about several visits to hospitals. A pattern could be noticed in the different interviews, as the different women said that their husbands attended appointments or therapy sessions with them or their (grand)children. Respondent 4 said that her husband went with their grandchild to a specialized hospital, respondent 3 talked about her different rehabilitation and therapy sessions with a doctor or physiotherapist, which her husband also always attended with her. Respondent 1 also mentioned that during her medical appointments, when she was 24 and had a cancer, but also later now when she had to visit a doctor, her husband always went with her. Another habit in using healthcare is that they do not eat the hospital food, as it is prepared by strangers. But they eat food brought by family members like bouillon and meat (respondents 3 and 4).

However, they all mentioned that they were used to going to hospital. Respondent 1 had a surgery at the age of 24, but had not been back for a check-up for 17 years. When asked why she did not go for check-ups, she said: “you know” and shrugged.

The Roma who were interviewed had “no complaints about healthcare” but attributed all the problems to the diseases themselves (respondent 3). Respondent 3 mentioned that her husband did not want to go to hospital, “because he has never been there”. Respondent 3 had tried many different

types of therapy for her severe neck pain but after many different therapies wanted to stop because it all did not help.

Places With Healthcare

In a community building in the village, there was a paediatrician present on Mondays and Thursdays. The women said that they visited this paediatrician when the children were sick (respondent 3) but there was also a community nurse who visited them regularly and checked the children (respondent 4). The closest city with a hospital is 35 km away from their village, “only for emergencies the ambulance comes” ... “for the children sometimes” but it is “more convenient to go to a nearby village myself, to visit a health clinic” (respondent 3). Respondent 5 had also recently given birth in that hospital.

Employment and Health Insurance

“All have health insurance”, mentioned respondent 3, “so people keep a job for a while, not really permanently” to have health insurance (respondent 3). But they got everything covered: “all diagnostic tests and therapies for my neck problems [...] only the private doctors visit cost us 200 zlotys and we had to pay for the transport to [the city in which the therapy was]”. Expert 2 said that “the Roma often don’t have jobs but live on social assistance benefits” and added that “they know exactly what funds they are entitled to, e.g. for transportation costs to the hospital”.

Roma Assistant and Education

Respondent 3 said she was a Roma assistant at the local school, but the on-going neck pain for over 3 years made it impossible to carry out the job. But “the job was still in the family” she said, as her daughter-in-law (respondent 5) was now the Roma assistant, being the mediator between the school and the Roma community as well as the contact person “for potential projects in the village” for the Roma community (respondent 5). She was also in contact with expert 2, who said that the Roma assistant was an efficient way to communicate between the community and the school. But that it did not necessarily encourage education among Roma children. They are not stimulated by their parents or the community to get good grades at school: “when they do not possess the skills they should when they finish the school year, they are still promoted to the next year, there are no consequences” (expert 2).

Insights of Experts

Three different experts were interviewed about their insights into Roma health inequity. Expert 1 gave more insight into the differences between the Roma groups in Poland in regard to health. He stated that differences between the groups are mostly “that their members think the groups are

different". Yet, their time of arrival in Poland is different as is also mentioned in literature (Malyarchuk, Grzybowski, & Derenko, 2006; Talewicz-Kwiatkowska, 2014; Nowicka, 2008).

The expert added that the Kelderasha and the Polska Roma have a constitution of elders who rule the subgroups called 'natsias', which are groups of clans that are historically associated with a certain territory but are not necessarily living there currently. In the Kelderasha group, called Kris, which functions as a traditional court, and in the Polska Roma group it is called Celo, functioning as the Roma parliament. Bergitka Roma do not have this, but are divided into local communities and big families, ruled by elders.

The Roma live according to the principles of Romanipen, which expert 3 formulated as: "based on a bi-polar division of the universe into the 'pure' and 'polluted', so their life is defined by numerous rules of avoiding the mixing of the two spheres". Polska Roma therefore also approach health differently, as mentioned by expert 1 as follows: "the sphere of medicine is dangerous and full of potential pollutions in the traditional worldview, so a good Rom should for example avoid hospitals". For example, expert 3 spoke about a woman she visited. She had recently had her fifth child that was delivered with a caesarean section, but she did not stay in hospital but went home on the next day "as she had done with the other children" (expert 3).

The Romanipen of the Bergitka Roma is not based on a developed system of pollution taboos and relies but on a general sense of 'being Roma', but as mentioned before, the expert added that both Polska and Bergitka Roma generally do not want interventions in sexual and reproductive health. The current generations of Polska Roma are more often using healthcare facilities when needed, said expert 1 as he "has the feeling that contacts with medicine are liberating". Expert 1 saw the Romanipen principle not as a factor influencing the health disparities among the Roma. Factors that do play a role in his view are "lower level of education, poverty and difficulty to access health services for some groups living in the mountains" (expert 1).

The other experts mentioned the relations between the different Roma groups in Poland. Expert 3 often experienced difficulty in gathering Roma people for vaccination programmes or health trainings, as they "often quarrel among the different families and groups". "People would not come to the place where the vaccinations were given, as they would meet Roma of other groups there". Therefore, "vaccinations were done now by a community nurse, visiting the Roma at home" (expert 3). Expert 3 said that some children in the community she worked with did not go to kindergarten as mothers said: "they would meet Roma children from other groups"; she stressed that it was "not a problem for them that they would integrate with the general population but it was a problem that they would socialize with the other Roma groups".

Intermarriage between the different Roma groups was also not allowed, mentioned expert 2. Expert 1 said that intermarriage between different

Roma groups was nowadays more common, although “Bergitka Roma are still sometimes regarded as ‘second rate’ Roma by people of the Polska Roma group” (expert 1).

At the bus station where the first interviews were done, there was a Roma couple working at the public toilet. Expert 2 explained that this was uncommon among Polska Roma, as this kind of job does not conform to Romanipen. These people are Bergitka Roma and are allowed as “Bergitka Roma do not conform to Romanipen principles” (expert 2). Expert 2 said that the Roma sometimes started studying medicine or nursery but seldom went into practice because that did not correspond to Romanipen principles. However, respondent 1 stated that when she was 24 years old and had a surgery at a hospital in southwest Poland, a health professional helping her looked at her papers and said: “you are one of us”, meaning that she was herself also a Bergitka Roma.

Media View

A couple of Polish newspaper articles regarding Roma health were analysed as an example. Two simple articles in a local newspaper and one in the national internet media report on cases of infectious disease outbreaks in Roma communities. The first article was published in *Gazeta Wroclawska*, in which a professor and a provincial consultant on infectious diseases were interviewed (Wojciechowska, 2014). What was striking was that the Roma village was described in the article as ‘a home for infectious diseases’ (Wojciechowska, 2014). This may come across as diminishing the living environment and blunt as it is said without explanation or reasoning. In the article, they also mention that at the infectious disease hospital, there are often cases reported of the Roma with rubella, small-pox or mumps. ‘Often’ is rather arbitrary and it is not clear where these ‘data’ come from, as prevalence data are not collected on ethnicity in Poland (Parekh & Rose, 2011). The provincial infectious disease consultant was quoted in the article as saying “if they want to get the Roma to the hospital, they run away” (Wojciechowska, 2014). This portrays the Roma community as being immoral and senseless in not going to the hospital. This creates the assumption that the Roma are afraid of treatments. This poses the question of who is formulating the problem. Whose voice is represented in this article? Is the problem that is represented in the article the ‘real’ problem and who decides what the problem is? (Bacchi, 2016). The consultant adds that they “should adapt to our healthcare standards” (Wojciechowska, 2014). The article uses the they-against-us, the so-called ‘othering’ narrative. The Roma: ‘they’ are not part of the majority group which is the group whose representative is reporting, and thus in charge, that is ‘us’. This portrays the groups as being opponents and creates polarization (Setti, 2015). Also, this assumes that ‘we’, whoever that signifies, have the right to set the standard of healthcare and have the power to

force ‘others’ to meet this standard, which stresses unequal power relations (Lauritzen & Nodeland, 2018).

The second article, in *Metro Gazeta*, sets off with explaining that the Roma community in the voivodeship was provided with free medical care, as “they are part of the community and there is the need to protect the other inhabitants of the province” (Romowie..., 2006).

The third article was published in on-line *Gazeta.pl*, in which a female scientist and a member of Roma society was interviewed (Jankowska, 2020). The article explains that the Roma community have been the object of aggressive rhetoric associated with stereotypical perception of the community for years. During the spread of the COVID-19 epidemic, the health situation of the Roma became much more dramatic than that of other citizens of the country. The desire to help the community by providing the right amount of protective equipment, including masks, met with hostility among internet users. Ensuring isolation for family members in difficult housing conditions became completely impossible. This story uses again the ‘othering’ narrative (Lauritzen & Nodeland, 2018), which implies a sense of the Roma community in opposition to other residents of the country. And the solution of free medical care may not be addressing the underlying problem of the health gap between the Roma community and the general population (Bacchi, 2016).

7. Discussion

The main insights into the views of the Roma, Roma experts and society on Roma health will be discussed, along with the limitations and the implications of these insights.

The main insights into the Roma views are that the Roma who were interviewed talked freely about their health, shared their health problems and spoke about the health problems of their family members. They said that many of their family members suffered mainly from cardiovascular diseases, also children suffered from different diseases. They shared many experiences of them going to healthcare facilities and one of the interviewed women attributed her problems to her health issues, not to the healthcare facilities (respondent 3).

Another insight into Roma health and wellbeing was provided by the qualitative observations that were made at the site of the interviews. Many men of working age were sitting on sofas outside in the middle of the day. This could confirm the opinion of expert 2 that “currently, when most of the former workplaces are closed, Roma are not working but live on social assistance”. Although this is out of the scope of this research and only one observation, the observed behaviour does say something about the lifestyle of these particular men. But lifestyle is an important factor influencing health.

The main insights that were provided by the views of Roma experts on the Roma health inequity problem are the differences between Roma groups

in Poland. There are differences in how Polska Roma and Bergitka Roma (the two major groups in Poland) view health and especially healthcare. Expert 1 explained that “medicine is regarded as ‘polluted’, which means that they cannot go to a hospital as good Roma”. Expert 3 spoke about a woman in her work field who went home on the next day after she had had a caesarean section. Although the Bergitka Roma who were interviewed may have different habits around medical consultancy visits, like the husband attending the therapy sessions and doctor visits with his wife, they do not shun healthcare facilities. They are used to bringing their own food to relatives in hospital, as it cannot be prepared by strangers, but in general Bergitka Roma do not conform to the Romanipen code, it is not part of their culture (Talewicz-Kwiatkowska, 2014; Cianciara, Nowicka, & Sitarek, 2012; Nowicka, 2008). Why one group does conform to it and the other does not can be explained by their recent history, explain Talewicz and Nowicka in their research, as the Bergitka Roma have a sedentary background and the Polska Roma have a more recent nomadic lifestyle, which means that Polska Roma had to protect their culture from other cultures when they moved around the country while Bergitka Roma assimilated more in their permanent neighbourhoods (Talewicz-Kwiatkowska, 2014; Nowicka, 2008; Nowicka & Witkowski 2019). This also overlaps with the statements of expert 1, although in his view, Polska Roma also “liberated themselves from the strict rules of Romanipen with regard to medicine”.

This difference between Polska Roma and Bergitka Roma also becomes clear when looking at job choices. Expert 2 explained that the couple that was observed, working at the public toilet at the bus station, had already worked there for many years. One of the Roma women said during the interview that she was treated by a Roma medical professional (respondent 1). These jobs are described as being despised by Romanipen (Grzymała-Moszczyńska, Barzykowski, Kosno, & Dzida, 2019; Talewicz-Kwiatkowska, 2014). But for Bergitka Roma, these jobs are regarded as good, as they bring income and appreciation (Talewicz-Kwiatkowska, 2014). Although Bergitka Roma do not conform to Romanipen in regard to health, expert 1 said that neither Bergitka nor Polska Roma want healthcare interference with sexual and reproductive health, “regarding contraceptives, reproductive rights and women’s sexuality”. This was also observed and heard during the interviews with the Bergitka Roma women, as respondent 2 stated that she had eleven children and “younger generations still had many children”.

Another main finding in regard to the Roma and expert views on Roma health is that it is difficult to find people willing to be interviewed. It is not surprising as the history of the Roma, as described in the literature review, made them suspicious towards authorities and institutions, including universities and research (World Bank, 2019).

A part of the reason why people in the network of the researchers of this study have refused an interview may be that they are mainly from

and around Warsaw and the Roma who live in this area in Poland belong to the Polska Roma, as expert 1 explained and is mentioned in literature (Grzymała-Moszczyńska, Barzykowski, Kosno, & Dzida, 2019). So the Roma contacted through our network may be more strictly conforming to Romani, which may also include talking about health with researchers. The Bergitka Roma community that was visited in the Carpathian Mountains were willing to be interviewed, because they differ in the worldview also in regard to medicine, as expert 1 explained as well as is mentioned in literature (Gruber, 2009; Malyarchuk, Grzybowski, & Derenko, 2006; Belak, Madarasova Geckova, van Dijk, & Reijneveld, 2017).

The main insights that the newspaper articles give into the views of society on Roma health are that the denigrating view on Roma is still present in society, as some statements created a narrative of 'othering' (Lauritzen & Nodeland, 2018). This creates a division between the Roma and the general population, like the literature that states that they are regarded as migrants, not as a minority being part of Polish society (Guglielmo & Waters, 2005). This creates and emphasizes unequal power relationships between the Roma community and the general community or the Roma and the healthcare minister or expert. The first two articles sound patronizing and suggest that the general population should be scared and needs to be protected from the Roma community.

8. Limitations

One of the limitations is a small number of data sources. The method for the selection of the village in which the interviews and observations were carried out can also form a limitation to this study. The village was also one of the Roma communities in which expert 2 also did research but not focused on health. This, on the one hand, provides a more balanced and in-depth view on one community, as the expert's view is not regarded as the only view but the community members can share their knowledge too. On the other hand, this narrows the scope of this study to one particular village, although there are many more different Roma communities in Poland.

There are much more press and scientific publications than those which have been analysed here but due to the length of this paper, there is no possibilities to look at a larger number.

A limitation of the design of this study is that in qualitative research, the researcher is the key measuring instrument (Creswell, 2014). The researchers used different data sources to analyse the different views on Roma health, but they are not neutral entities. When analysing the data, researchers will always have a subjective view on the data because of their background (culture, gender, socioeconomic status, history, experience, knowledge, etc.). The aim of this study is to gain insight into different views but the

researchers are not objective so no objective insight into these views can be reported. The researchers themselves are also 'someone looking' at the topic of Roma health. Nevertheless, this design was the most suitable method to gain insight into the different views that are addressed in this study and the researchers were aware of this limitation and critically reflected on the process of data collection and analysis to be aware of subjective reporting.

This study forms a good starting point for further research. This is a small-scale qualitative study, but already these findings show the diversity in views and viewpoints on Roma health in Poland.

The policy in Poland that addresses the health issue of Roma: the national Roma integration policy is targeted at the whole Polish Roma population, homogeneously, although the target population is rather heterogeneous. This is also mentioned in the evaluation report on Roma integration in Poland which says about Roma health that although diversity within the Roma population was highlighted in the policy, it "proved to have limited capacity to deal with diversity within the Roma population" (European Commission, 2018).

Although this is a small-scale study, it shows the importance of diversifying policies in addressing the Roma health gap. Already in Poland, with a relative small number of the Roma, there is a diversity in views on health among them. This means that across Europe there is an even greater diversity among the different groups of the Roma. This means that more in-depth research on the community level is needed on the EU level to gain insight into the different Roma groups across countries.

This study shows not only the diversity in views among Roma groups within Poland but also the change of these views in time, as conformation to Romanipen principles is relaxing in younger generations (expert 1), so their view on health and healthcare is changing. This study implies that further in-depth research is needed that includes different viewpoints in order to make evidence-based, effective and appropriate policies to close the health gap between the Roma and the general population.

We must remember that national and EU organizations should not repeat the historical errors of organizing various dimensions of the socio-economic life of the Roma community without respecting their history, tradition and culture.

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