



The health of segregated Roma:

first-line views
and practices

Andrej Belak

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**first-line views
and practices**

**A case study
in Slovakia using
ethnographic
methods**

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Stellingen

Behorende bij het proefschrift

The health of segregated Roma: first-line views and practices

Andrej Belak

2nd of October 2019

1. Segregated Roma are also being oppressed through their self-exclusionary hopes and tastes.

Chapter 3 of this thesis

2. Pushed and pulled towards the so-called margins, most segregated Roma become skilled at escaping the relative disadvantages of life standard in the so-called centers.

Chapter 4 of this thesis

3. Many people who happen to serve segregated Roma feel that such position gradually forces them to choose between useless burnout and cynical neglect.

Chapter 5 of this thesis

4. Trusting segregated Roma with more decision power and resources causes many of them to challenge the local structures that oppress them.

Chapter 6 of this thesis

5. It would require a rather explicit selection process to make any risky genes concentrate in any Roma group – much more selective than Roma history could lead to.

Chapter 7 of this thesis

6. Antigypsyism drives the poor health status of the Roma, mostly because most people involved, including segregated Roma, do not understand that it is so.

Discussion of this thesis

7. We cannot claim to have formulated a convincing denial of the inequality of the human races, so long as we fail to consider the problem of the inequality — or diversity — of human cultures, which is in fact — however unjustifiably — closely associated with it in the public mind.

Claude Levi-Strauss

8. We're all going to die, all of us, what a circus! That alone should make us love each other but it doesn't. We are terrorized and flattened by trivialities, we are eaten up by nothing.

Charles Bukowski

9. We live in a world where we have to hide to make love, while violence is practiced in broad daylight.

John Lennon

10. We are lost, but other animals point to the right road. They are the right road.

John Zerzan

To my former family on the 9th floor, with pain

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ethnographic methods

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This thesis will be defended in public on

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Contents

Chapter 1 Introduction	13
Chapter 2 Methods	35
Chapter 3 Health-endangering everyday settings and practices in a rural segregated Roma settlement in Slovakia <i>Published in BMC Public Health 17(1):128</i>	39
Chapter 4 Why don't segregated Roma do more for their health? <i>Published in International Journal of Public Health, 2018, 63(9):1123-1131</i>	69
Chapter 5 Why don't healthcare frontliners do more for segregated Roma?	97
Chapter 6 How well do health-mediation programs address the determinants of the poor health status of Roma? <i>Published in International Journal of Environmental Research and Public Health, 2017, 14(12)</i>	143
Chapter 7 Do Roma and non-Roma patients need different care? <i>Published in International Journal of Public Health, 2019</i>	163
Chapter 8 Discussion	169
Summary/Samenvatting/Zhrnutie	193
Acknowledgements	211
About the author	213
SHARE Theses	215
KISH Theses	217
References	221



Chapter 1

Introduction

This thesis assesses the views and practices first of segregated Roma and then of health system professionals in Slovakia regarding the poor health status of segregated Roma in the country. It aims to contribute to the understanding of the health inequalities between segregated Roma and the general populations in Central and Eastern Europe (CEE). In this chapter, we first introduce the Roma people and then provide evidence on their mostly poor societal and health status in the CEE region. We then review what is already known about the causes of these health inequalities. Next, we sum up what has been attempted to alleviate these inequalities thus far and to what limited results. Then, we discuss what knowledge the pro-equity efforts have been lacking, and why qualitative exploration of first-line views and practices is a promising strategy for delivering it. After that, we introduce ethnographic research methods as a well-suited toolkit for such an exploration. Finally, we outline how we conducted this kind of research among segregated Roma in Slovakia.

1.1 The Roma

The Roma, a people concentrated mostly in the CEE region, Turkey and Spain (see Figure 1.1), present one of the largest and internally most variable ethnically defined populations in Europe. Middle estimates of the population's current size exceed 10 million (EUC 2019; EUFRA et al. 2012). No Roma have ever attempted to form a common, geographically defined nation state, perhaps mainly due to their shared ancestors' scattered and relatively late arrival to Europe in the Middle Ages (i.e. from the Indian sub-continent, originally) (Crowe 2007; Fraser 1995; Iovita et al. 2004; Martinez-Cruz et al. 2016). Instead, the Roma have continued to live as ethnic minorities, significant, albeit only partially registered officially and politically unorganized (EUFRA 2018b; EUFRA et al. 2012). Consequently, compared to other ethnically defined European populations (such as the Dutch), the Roma show much greater variability in most examined aspects (Barany 2002; Guy 2001; Stewart 2011). For example, many people of Roma origin use different ethnonyms (e.g. Kale, Sinti, Gitanos), speak different mother languages (Bakker 2012; Matras 2002) and engage in rather distinct mutual relations and social norms (Marushiakova et al. 2001; Stewart 2013; Tcherenkov et al. 2004).

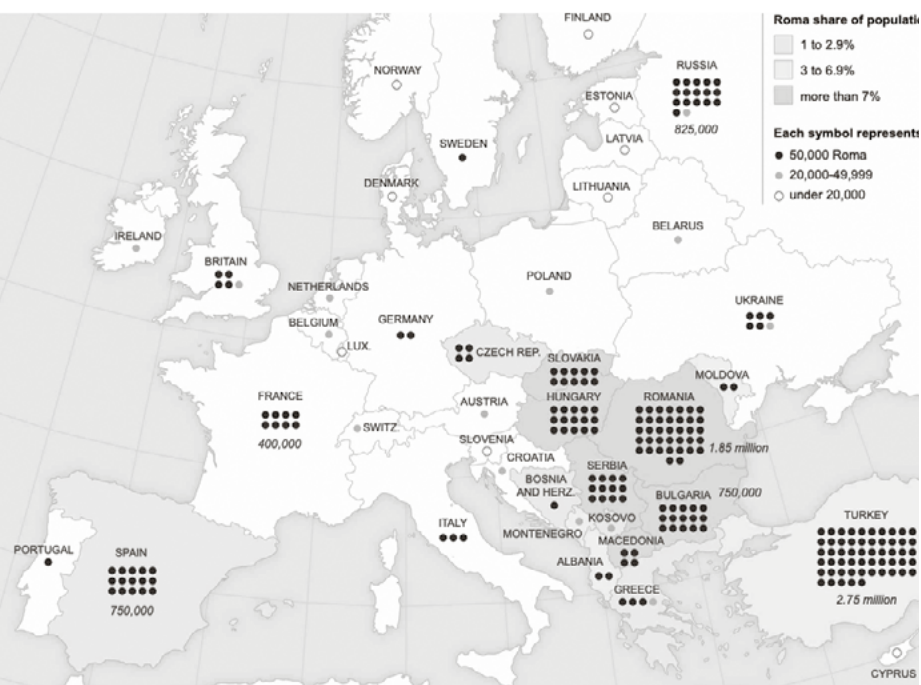


Figure 1.1 The distribution of Roma people in Europe (Bilefsky 2013)

1.2 CEE Roma and the health inequalities concerning them

In their respective home countries, large proportions of CEE Roma reside in segregated enclaves, occupying the lowest societal positions and frequently experiencing harsh treatment. Across the region, large parts of the Roma minorities continue to live both physically and socially segregated from the local non-Roma (e.g. attending schools and other public services separately). They often live in extremely substandard, third-world-like housing conditions (lacking electricity, potable water, sewerage, etc.) on the outskirts of villages, towns and in urban ghettos (EUFRA et al. 2012; Picker 2017). For these Roma, extremely low rates of education, employment and incomes have been shown to persist over the past two decades (EUC 2004; EUFRA 2018a; EUFRA et al. 2012; FSG 2009). Moreover, regardless of their level of segregation, CEE Roma face ethnic discrimination and frequently experience antigypsyism, a specific form of racism deeply embedded in local non-Roma traditions, explicitly targeting Roma, derogatorily imagining and denoting them as “Gypsies” (“cigáni” [tsigany] in Slovak) (Albert et al. 2016; EUFRA 2018b; Grill 2017; Stewart 2012).

Although not comprehensive, published evidence also convincingly indicates steep and persistent health inequalities between the Roma and the general populations across the CEE region. Due to the lack of systematic surveillance (ERRC 2013; EUC 2014), the available evidence entails only academic studies and the reports of non-governmental organisations (NGO). Academic studies are increasingly numerous and rigorous, yet thematically rather specific, i.e. focusing on specific diseases and related factors and far from everywhere (Cook et al. 2013; Hajioff et al. 2000; Orton et al. 2017). Large-scale NGO surveys, carried out regularly since mid-2000s, are broader in their scope, i.e. focusing on health and related determinants in general and in the whole region. However, these reports rely mostly on self-reporting and lack rigorous scientific peer review (EUC 2014). For most countries, scientific studies remain insufficient, both in quantity and in quality, to draw clear conclusions regarding specific health problems, especially clinical outcomes. Convincing rigorous evidence has only been accumulated on disparities in mortality risks and in self-reported health (Cook et al. 2013; Hajioff et al. 2000). Reports and scientific studies based on large-scale NGO survey data support this general picture, offering a plethora of additional indices and details, some of them further discussed below (e.g. EUFRA 2018a; EUFRA et al. 2012; FSG 2009; Masseria et al. 2010; UNDP 2012).

1.2.1 Roma vs non-Roma health inequalities in Slovakia

In this thesis, we focus on health inequalities between segregated Roma and other major populations in Slovakia, which traditionally belong among the most studied scientifically (Cook et al. 2013; Hajioff et al. 2000), and which congruently both exemplify and further extend the above CEE picture (cf. Bartosovic 2016; Ginter et al. 2005; Sprocha 2011). For Slovak Roma at large, demographic analyses have shown higher mortality rates and shorter life-spans (Rosicova et al. 2011; Rosicova et al. 2015; Sprocha 2014; cf. Šprocha et al. 2018) (see also Figure 1.2). For Roma living in segregated enclaves, i.e. for approximately 40% of 450,000 Slovak Roma (Musinka et al. 2014) (see also Figure 1.3), clinical studies have shown greater burdens of various communicable and non-communicable diseases across the life-course (e.g. Antolová et al. 2018; Antolová et al. 2016; de Courten et al. 2003; Drazilova et al. 2018; Halánová et al. 2018; Hasajova et al. 2014; Kristian et al. 2013; Rosenberger et al. 2014; Rudohradska et al. 2012; Sudzinova et al. 2015; Sudzinova et al. 2013; Veseliny et al. 2014). Slovak Roma have also been found to rate their health as worse compared to their non-Roma counterparts, including

with a gradient according to levels of segregation (e.g. Davidova et al. 2010; Filadelfiova et al. 2012; Filadelfiova et al. 2007; Geckova et al. 2014; Jarcuska et al. 2013; Kolarcik et al. 2009; Silarova et al. 2014).

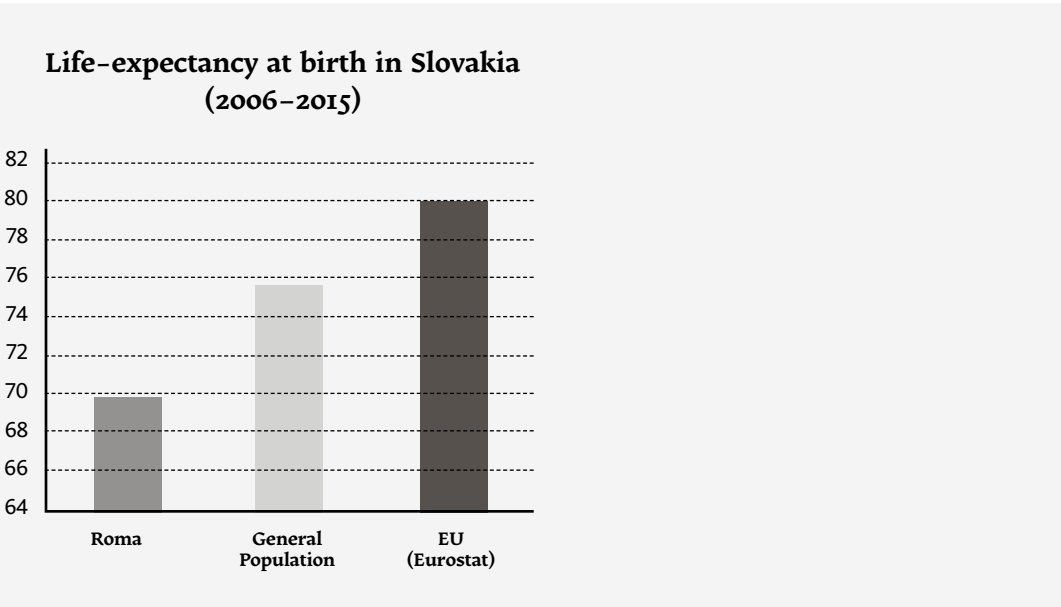
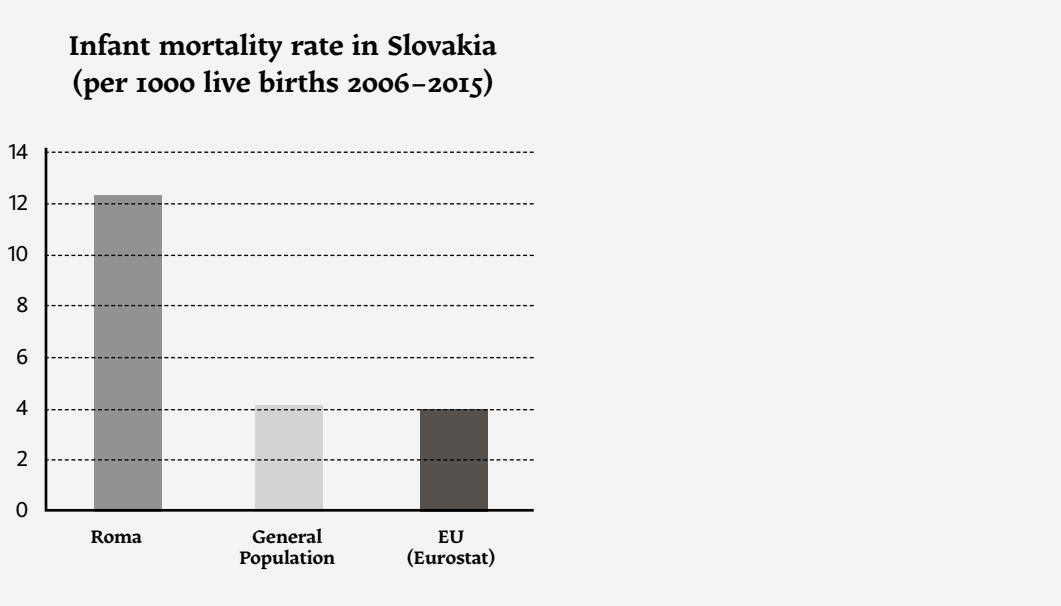


Figure 1.2 Health indicators for Roma and the general population in Slovakia, and the EU average

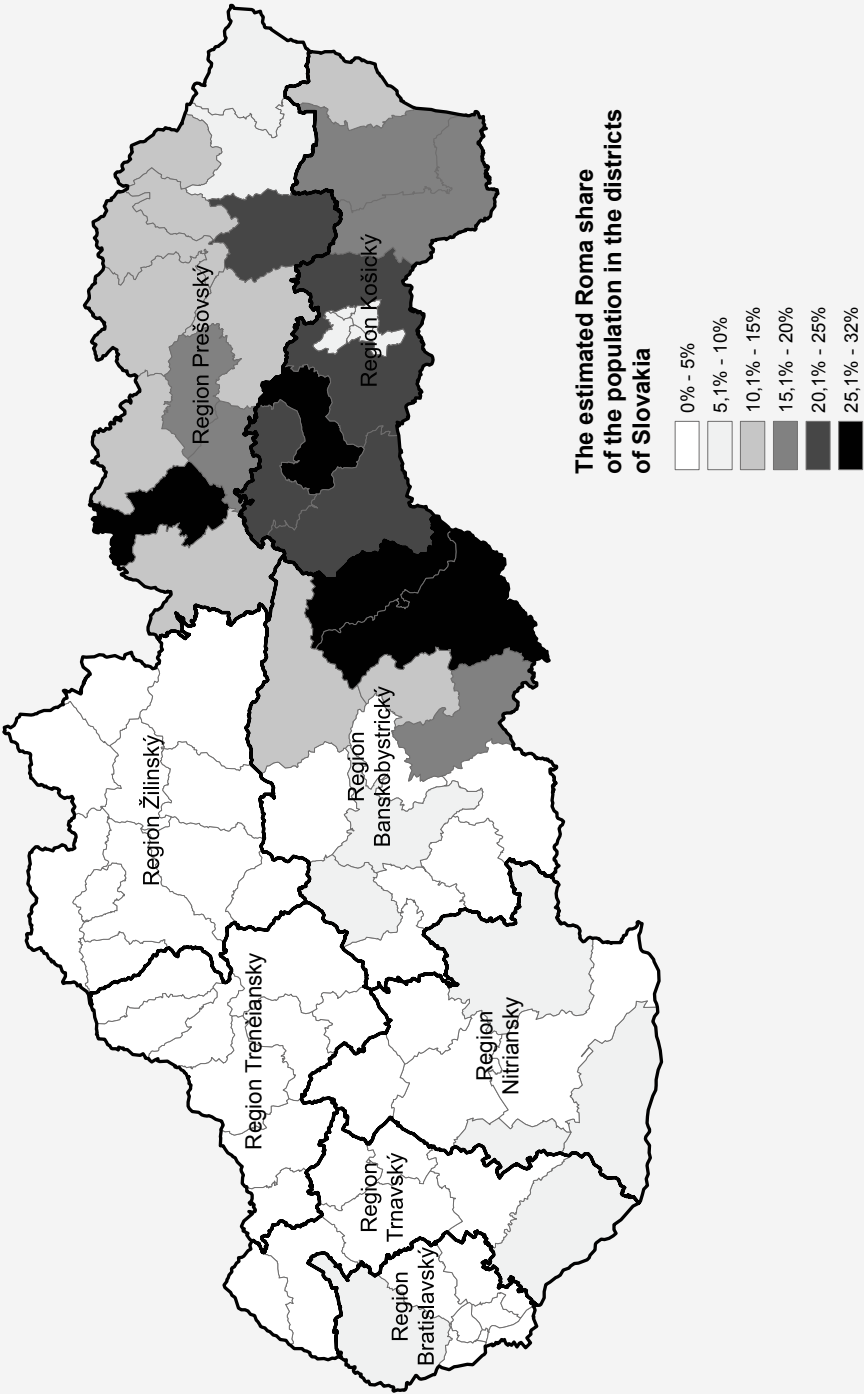


Figure 1.3 The distribution of Roma in Slovakia
Estimated share of Roma in the population (Brunn et al. 2018)

1.3 Pathways maintaining CEE Roma health inequalities: hypotheses and findings

Large-scale NGO surveys consistently show that CEE Roma are more exposed to circumstances that are known to be detrimental for health and to maintain social health inequalities (e.g. Diez Roux 2012; Krieger 2011; WHO 2010a; WHO 2013a) (health-endangering exposures; see also Figure 1.4). According to these surveys, with increasing levels of segregation compared to the general populations CEE Roma face more adverse material circumstances, health-related behaviours and psycho-social pressures, while simultaneously not using appropriate healthcare services of comparable quality and as often (EUC 2014; EUFRA 2018a; FSG 2009; UNDP 2012).

Scientifically, higher health-endangering exposures among CEE Roma have been corroborated most rigorously, first by comparative studies on material conditions and lifestyle-related exposures in children (Cook et al. 2013; Orton et al. 2017) and lately also by studies on healthcare access and quality (e.g. Andreassen et al. 2018; Arora et al. 2016; Duval et al. 2016; Földes et al. 2012a; McFadden et al. 2018; Sándor et al. 2018; Stojanovski et al. 2017; Tambor et al. 2014). Overall, studies focusing on material circumstances and health-related behaviours in Roma adults, including aspects of sexual and reproductive health, support this picture. However, scientific studies mostly do not document the whole region, as most are only focused on single countries (e.g. Andreassen et al. 2018; Cook et al. 2013; Dimitrova et al. 2013; Dimitrova et al. 2018; Janevic et al. 2017; Kamberi et al. 2015; Kósa et al. 2015; Nikolic et al. 2015; Sedlecky et al. 2015; Walfisch et al. 2013; Zeljko et al. 2013).

Findings on other determinants of health in CEE Roma are even more varied and sparse. First, findings on exposures to adverse psychosocial circumstances are rather varied (Bobakova et al. 2012; Dimitrova et al. 2013; Dimitrova et al. 2014; Dimitrova et al. 2018; Dimitrova et al. 2017; Kamberi et al. 2015; Kolarcik et al. 2010; Kolarcik et al. 2012; Kolarcik et al. 2015). Second, despite the long-term emphasis in CEE research on genetic differences (Cook et al. 2013; Hajioff et al. 2000), no genetic study has so far identified hereditary traits having significant health effects in the group as such, i.e. effects beyond increased susceptibilities to some rare health conditions (e.g. Diószegi et al. 2017; Fiatal et al. 2016; Iovita et al. 2004; Kalaydjieva et al. 2001; Martinez-Cruz et al. 2016; Pikó et al. 2017; Szalai et al. 2014). This is in line with findings on other ethnic disparities in indicating complex reproductive segregation patterns faced by minority ethnic groups (Bhopal 2015; Dressler et al. 2005; Smith 2000).

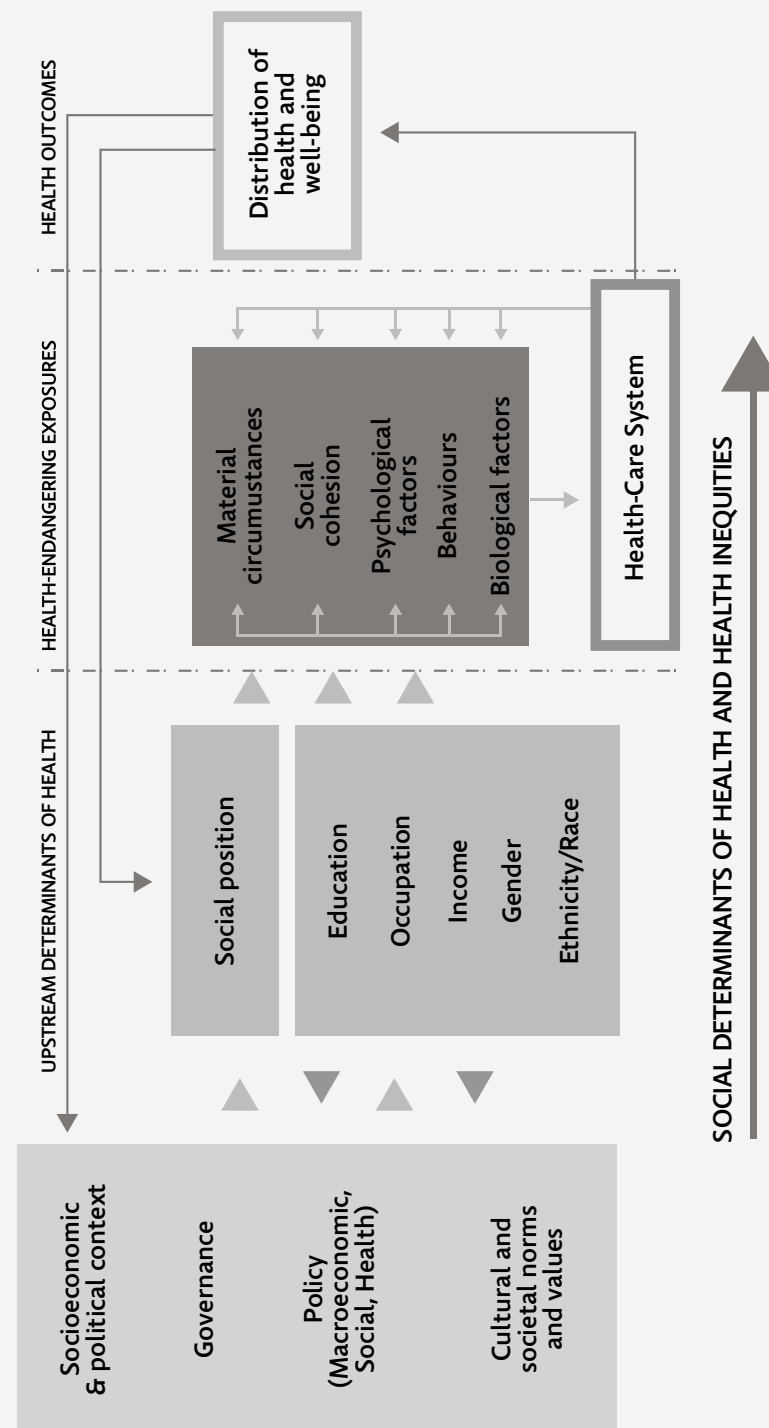


Figure 1.4 Conceptual framework on social determinants of health of the World Health Organization (WHO 2010)

Scientific evidence on CEE Roma regarding the more “upstream”, indirect pathways, i.e. the determinants of high exposures to detrimental circumstances faced by worse-off groups (see Figure 1.4), is much patchier and less conclusive. Most early studies focused on the correlations between measures of socioeconomic position (SEP; see Figure 1.5) and health-related measures (Cook et al. 2013). Overall, these studies showed that CEE Roma have much less formal education and a lower income, and that this is associated with more adverse health-related exposures and poorer health (e.g. Janevic et al. 2012; Masseria et al. 2010; Voko et al. 2009). However, most of these studies did not include non-disadvantaged Roma, and some used disputable indicators of ethnic affiliations (Janka et al. 2018). Moreover, many of the studies showed systematic differences that could not be explained by differences in SEP and results regarding the same relationships varying across CEE. Consequently (Reijneveld 2010), and in line with findings from elsewhere (Dressler et al. 2005; Smith 2000), these studies clarified neither the exact causal relations between SEP and CEE Roma ethnicity nor how exactly low SEP turns into poor health in the case of CEE Roma

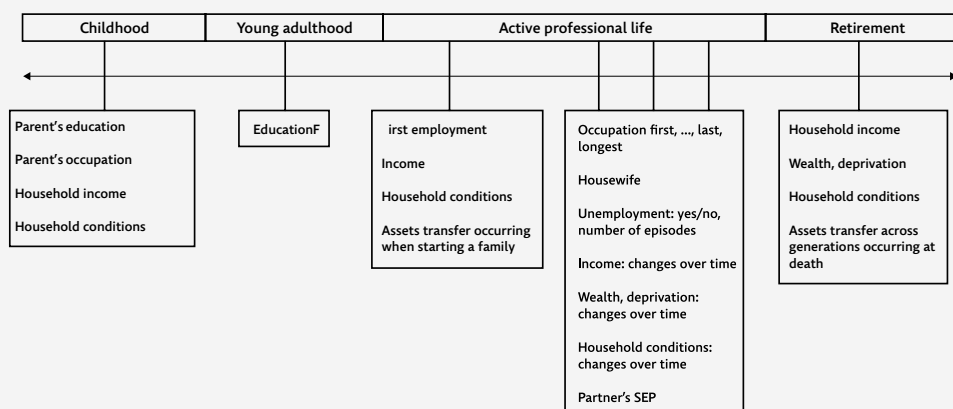


Figure 1.5 Examples of indicators measuring life course socioeconomic position (Galobardes et al. 2006)

Various recent studies on health-related discrimination and on health-related social norms and practices have now shown that these two determinants may play important roles in shaping the related exposures of CEE segregated Roma. Several studies identified a variety of discriminatory and racist practices towards the Roma across all organizational levels of the studied healthcare systems (e.g. Colombini et al. 2011; George et al. 2018; Janevic et al. 2017; Janevic et al. 2011; Rechel et al. 2009). Recent comparative studies in this area also show specific contributions of discrimination (Janevic et al. 2015; Janevic et al. 2017; Kolarcik et al. 2015). Regarding health-related social practices in Roma, both qualitative (e.g. Andreassen et al. 2017; Janevic et al. 2011; Kelly et al. 2004; Stojanovski et al. 2019) and quantitative studies (e.g. Čvorović 2018; Čvorović et al. 2017; Čvorović et al. 2018) have identified rather complex, context-dependent social strategies and adaptations, especially with respect to sexual and reproductive health of Roma women. Findings from quantitative studies examining how collective identities form in Roma youth and how these identities relate to well-being show a similar complexity (Dimitrova et al. 2018; Dimitrova et al. 2017). In sum, all this research further supports the idea that some upstream pathways might partially vary for different CEE Roma, perhaps depending on changing social contexts both within and outside Roma communities. Studies assessing the impacts of policies, interventions and more distal determinants of CEE Roma health remain scarce and mostly inconclusive (Kaluski et al. 2015; Molnár et al. 2010; Orton et al. 2017; Sándor et al. 2017).

1.3.1 Pathways in Slovakia

Most of the above-discussed patterns of health-endangering exposures faced by Roma have been relatively well studied for Slovakia. Rigorous scientific studies have found the segregated Roma in Slovakia to live in unhealthier material circumstances (Frisman et al. 2015; Majdan et al. 2012; Škobla et al. 2016) (for an illustration, see Figure 1.6), to smoke and use illicit drugs more frequently (Babinska et al. 2013; e.g. de Courten et al. 2003; Hubková et al. 2018; Vazan et al. 2011), to eat an unhealthier diet and be more obese (Hijova et al. 2014; Krajcovicova-Kudlackova et al. 2004; Petrásová et al. 2014) and to engage in less healthy physical activities and incur more injuries (Babinska et al. 2014; Babinska et al. 2013; Kolarcik et al. 2010). Slovak segregated Roma were also found to face greater healthcare-access barriers (Bobakova et al. 2015; Jarcuska et al. 2013; Kolarcik et al. 2015) and to rate their health as worse (Geckova et al. 2014; Kolarcik et al. 2009).



Figure 1.6 Material circumstances in urban (up) and rural (down) segregated Roma enclaves in Slovakia
(© Michael Biach & Martin Slavin).

These findings are in line with the findings from numerous local NGO surveys (CRR 2017; Davidova et al. 2010; Filadelfiova et al. 2012; Filadelfiova et al. 2007; FSG 2009; Popper et al. 2011). Similar to further findings for CEE, genetic research among Slovak Roma has shown very few health-relevant differences except for higher frequencies of gene mutations causing rare diseases, indicating socially determined adverse reproductive patterns (isolation and endogamy) (e.g. Bozikova et al. 2015; Bôžiková et al. 2012; Dluholucký et al. 2017; Gabrikova et al. 2015; Gabrikova et al. 2013; Ivanov et al. 2014).

In contrast to the general CEE picture, however, rigorous comparative studies in Slovakia have also found some equal or lowered adverse health-endangering exposures of segregated Roma, especially among youth. Contrary to public assumptions, compared to local non-Roma segregated Roma adolescents were less or equally likely to consume alcohol (Babinska et al. 2014; Kolarcik et al. 2010), to engage in delinquent and aggressive behaviors (Kolarcik et al. 2016) and to engage in promiscuous relationships (Babinská et al. 2017; Drazilova et al. 2018; Halanova et al. 2014; Veseliny et al. 2014). At the same time, Roma youth have been found to face less adverse peer pressure (Bobakova et al. 2012), to have more functional social support (Bobakova et al. 2015; Kolarcik et al. 2012) and to fare better in selected well-being measures (Kolarcik et al. 2012).

Regarding “upstream” pathways, the evidence for Slovakia well exemplifies the patchy CEE picture. Studies examining possible mediating roles of low SEP here, too, have struggled with including enough high-SES Roma and have, too, not been able to explain all the differences in the exposures and outcomes they identified (Geckova et al. 2014; Kolarcik et al. 2009; Kolarcik et al. 2010). This research has thus likewise mostly shown that segregated Roma seem to be in a worse position than non-Roma with a low SEP. Originally, an extensive local study by Geckova et al. (2014) confirmed barely any significant associations between SEP and various health-related measures also within segregated Roma enclaves. In other words, similar patterns of health-deterioration might apply to most people living within segregated Roma enclaves in Slovakia, regardless of varying levels of education and income therein. Together, these findings also suggest a likely involvement of other “upstream” determinants for Slovakia, such as discrimination, specific health-related social norms within and outside segregated Roma enclaves, including health-related policies. Research on these topics has, however, been scarce until now (cf. Bosáková 2013; Kolarcik et al. 2015; Šprocha et al. 2018).

1.4 Pro-equity efforts targeting CEE Roma health inequalities

Over the past two decades, ambitious national plans have been set out across CEE “to close all the gaps” between Roma and non-Roma, explicitly including health as one of their key areas, initiated and driven mostly by international organisations (Brüggemann et al. 2017; Vermeersch et al. 2017). Approaching the inequalities as a developmental issue, the World Bank (WB) and the Open Society Foundation (OSF) gradually designed and negotiated the so-called Decade of Roma inclusion (DRI 2005), building mostly on the United Nations Development Program’s (UNDP) survey data and using their own funding and capacities. This WB and OSF initiative has so far been the largest and most significant pro-equity initiative explicitly addressing Roma disadvantages in Europe (Brüggemann et al. 2017; Vermeersch et al. 2017).

The DRI initiative of the WB and OSF gradually managed to involve other NGOs, government representatives and pro-Roma activists from most European countries with significant Roma minorities. By 2011 this resulted in an international Framework of National Roma Integration Strategies (NRIS). The NRIS consists of a series of country-specific documents, since adopted by the countries’ governments as their primary strategic guides for addressing local Roma vs non-Roma inequalities in several key areas, including health, up to 2022 (Brüggemann et al. 2017; EUC 2018a; EUC 2019). In parallel, the NRIS Framework has also been adopted by the European Commission (EC), which has become the leading donor of its implementation. Every 2-3 years over the past decade, the involved countries have continued to revise specific areas-dedicated NRIS targets and related indicators, so-called NRIS Action plans. These Action plans continue to be used most often as primary guides for agenda-setting, grant calls, progress evaluations, etc., also by non-governmental actors, such as NGOs, private donors, media or academics, shaping related policies (Brüggemann et al. 2017; EUC 2018a; Vermeersch et al. 2017).

However, until now the implementation of the NRIS Action Plans has remained slow at best and of questionable success, in great part also due to a lack of required knowledge. The Action Plans themselves have continued to lack coherence and clarity, especially regarding their targets, ownership and accountability as well impact measurement, according to all in-house, civil society as well as academic assessments (e.g. Brüggemann et al. 2017; EUC 2018a; EUC 2018b). As for actual implementation and outcomes of the Action Plans, many of the planned activities have continued to not get carried out at all, and if carried out, not as planned. Moreover, for most of the activities carried out both

their processes and effects have continued to be poorly evaluated. This has resulted in a lasting general impression, shared by stakeholders of all backgrounds and organizational levels, of only modest positive changes brought about by the initiative (Brüggemann et al. 2017; EUC 2018a; see also Figure 5; EUC 2018b)(see also Figure 1.7). As the most salient reasons behind the poor NRIS progress evaluators emphasize: authorities’ conceptual dilemmas (e.g. redistribution vs. recognition approaches), lack of political will to lead required processes, inability to facilitate sincere and effective involvement of the targeted Roma communities, and a lack of reliable and intelligible data (Brüggemann et al. 2017; EUC 2018a; EUC 2018b; Vermeersch et al. 2017) .

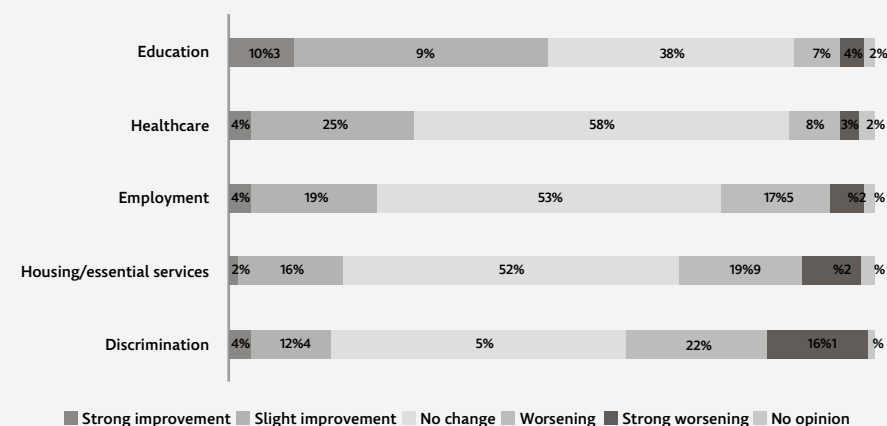


Figure 1.7 Changes in the situation of Roma since 2011
As perceived by stakeholders of the National Roma Inclusion Strategies (EUC 2018)

The developments regarding health illustrate very well the overall modest contributions of the DRI framework. In most reports, health has continued to be flagged as an area of some progress (e.g. EUC 2014; EUC 2018a; EUC 2018b), but such positive judgments are typically only based on assessing the levels of NRIS-related activities rather than their effects (ERRC 2013; EUC 2014; EUC 2018b; Fésüs et al. 2012). Positive judgements have been based only on mixed findings from self-report surveys (EUC 2018a; Sándor et al. 2017). Further, in most CEE countries the implemented activities have so far been limited to the states

facilitating, typically on a project basis and using international funding, a so-called health-mediation, i.e. programs focused on facilitating better access of segregated Roma to standard healthcare services (OSF 2011; cf. Thornton 2017; WHO 2013b). In other words, other potentially major determinants of Roma health have mostly remained unaddressed, e.g. the above-described substandard community infrastructures and adverse health-related behaviours in the segregated Roma enclaves, as well as the persisting discriminatory practices within healthcare systems (EUC 2014; Fésüs et al. 2012; Koller 2010). All of the above-described applies to Slovakia as well, despite the national health-mediation program in the country belonging among the most advanced (Belak 2015a; Belak 2015b; Slusna 2010).

1.5 The evidence gaps we targeted and the research strategy we chose

Based on the above overview of the available evidence, we identified and chose to target with our research the following three kinds of evidence gaps: How do the health-endangering exposures that CEE segregated Roma face translate into their (poor) health? What makes large portions of CEE segregated Roma face which exposures? And, on what, why and how well do the related health system interventions act? Our research strategy to fill these evidence gaps was qualitative, i.e. observing and discussing practices and views of people personally involved in a poorly understood area of interest (Gravlee 2011; Tolley et al. 2016). This strategy has been shown to be useful regarding such purposes. In any social health inequalities, the worse-off populations' health mostly becomes disproportionately damaged gradually, via the population members' everyday settings and activities (Diez Roux 2012; Krieger 2011; Trostle 2004; WHO 2010a). People with first-line experience regarding health in such settings, i.e. before all the worse-off people themselves and local health system professionals, usually possess rich knowledge regarding the pathways underlying the inequalities (Elliott et al. 2015; Frohlich et al. 2001; Popay et al. 1998; Trostle 2004). Exploration and analysis of such people's knowledge can advance the identification of local causal pathways between exposures and health. Given the interested and interactive embeddedness of such people in related wider societal structures (see Figure 1.8), the exploration of their knowledge might also clarify the roles of more "upstream" determinants driving the local patterns in health-endangering exposures.

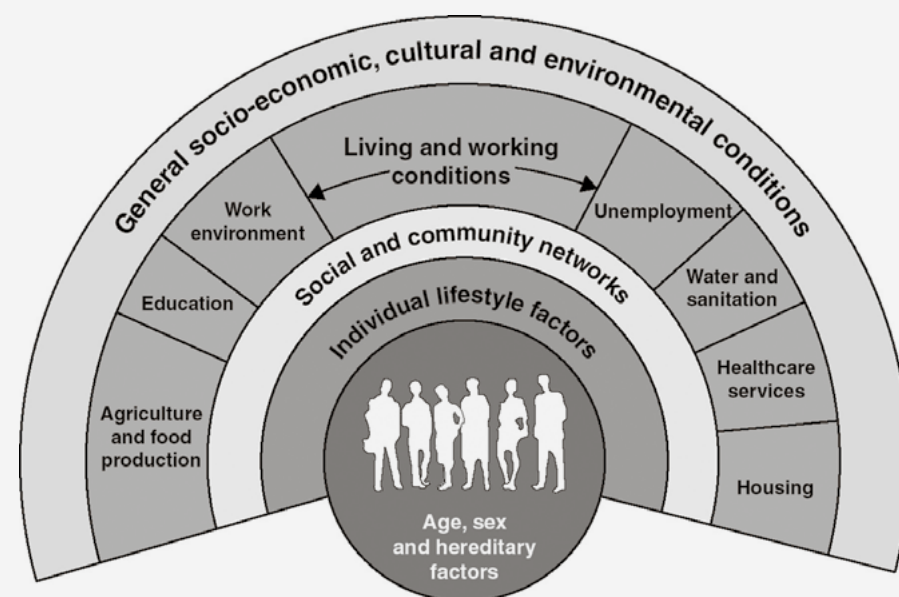


Figure 1.8 *The embeddedness of people in wider societal structures affecting their health* (Dahlgren and Whitehead 2006)

1.6 Ethnographic methods – our research toolkit

Ethnography, defined e.g. as “the study of social interactions, behaviours and perceptions that occur within groups, teams, organisations and communities” (Reeves et al. 2008), is known for delivering especially rich data and explanatory insights regarding human practices, including in previously unexamined or poorly understood social settings. Ethnography was originally developed as a methodology for systematic inquiry regarding social organizations and practices within previously completely unknown societies, but it has since become used everywhere as a specific qualitative-research approach (Hammersley et al. 2007). Compared to other qualitative-research approaches, such as open-question surveys or focus-groups, ethnography tends to deliver more detailed direct observations and more elaborate and candid interpretations of the studied people, especially where these might view researchers as representing outsiders they do not trust (Denzin et al. 2005; Hammersley et al. 2007; Reeves et al. 2008).

The ethnographic toolkit consists primarily of techniques enabling systematic acquisition of detailed direct observational, experiential and interpretative data regarding human practices. Originally, it consisted mainly of the researcher's long-term personal immersion in the social settings studied (extensive field work), including study of the local language and kinship relations, actively taking part in the studied practices (participant observation), building of close informal personal relationships with the people studied (rapport building) and sustained detailed documentation of observations (field notes, photography, audio recordings, etc.). Gradually, this basic toolkit has been extended to also include systematic examination of the same questions with a combination of different kinds of data-collection approaches (e.g. opportunistic and open-ended as well as purposeful and structured interviews) and data sources and theoretical perspectives (triangulation), and explicit reflection of relations, especially power-relations, with the people studied (reflectivity). Regarding data interpretation, building summaries based on themes emerging from the extensive descriptive data acquired (inductive qualitative content analysis) has remained the dominant ethnographic approach (see also Figure 1.9) (Hammersley et al. 2007; O'reilly 2012).

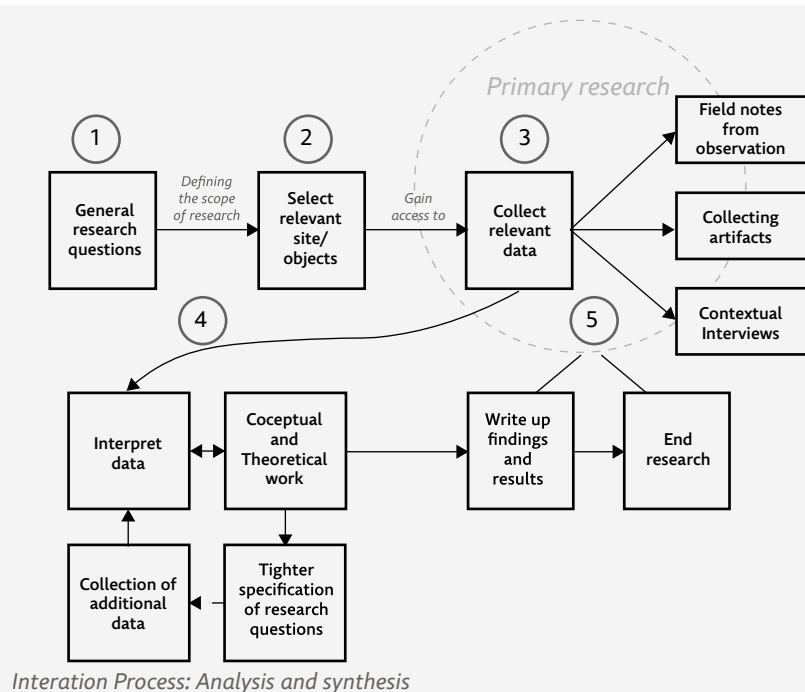


Figure 1.9 Standard research process in ethnography
(Aqeel et al. 2012)

The use of ethnographic methods in biomedical health research can yield original insights, including with respect to health inequalities. This use has a long tradition (Hahn et al. 1983) and keeps producing valuable insights both for clinical as well as for the public health practice (Hahn et al. 2009; Singer et al. 2011), despite being absent from standard curricula of most biomedical researchers (Pool et al. 2005; Trostle 2004). With respect to health inequalities, ethnographic work has added substantially e.g. to cultural competence within clinical practice (Kleinman et al. 2006; Streltzer et al. 2008), management of epidemics (Singer et al. 2003), the biosocial turn in global health (Farmer et al. 2013), structural competence in public health (Bourgois et al. 2017; Messac et al. 2013) and epidemiological research on ethnic disparities (Dressler 2005; Dressler et al. 2005).

Previous ethnographies on various Roma in Europe and an increasing number of biomedical studies applying ethnographic methods to specific topics regarding their health further indicate such approaches might be productive with respect to the evidence gaps we are targeting. For example, ethnographers of segregated Roma and comparable groups across the continent (e.g. Engebriksen 2007; Gay Y Blasco 1999; Okely 1983; Stewart 1997; Tauber 2006; Williams 2003) consistently document a relatively radical cultural resistance of these groups towards adoption of non-Roma standards. Many discuss this (e.g. Matras 2015; Stewart 2013) as one of the defining features of how segregated Roma construct their ethnic identities. Similar contributions on Roma social norms and practices emerge not only in local anthropological research on Roma (e.g. Grill 2017; Podolinska et al. 2014; Skupnik 2007), but also in some qualitative studies focused on specific health-related aspects in Roma and similar groups (e.g. Condon et al. 2015; Durst 2011; Jackson et al. 2017; Jesper et al. 2008; Kelly et al. 2004; OustinovaStjepanovic 2017; Roman et al. 2013; Tesăr 2012; Van Cleemput et al. 2007).

1.7 Thesis aims, research questions, model and outline

1.7.1 Aims

Based on the above, our general aim was to improve understanding of the health inequalities between segregated Roma and the general populations in CEE by exploring related views and practices first of segregated Roma and then of health system professionals in Slovakia. More specifically, our dissertation aimed to explore everyday practices and perspectives regarding three pathways that may contribute to this inequality: pathways between exposures and health outcomes, pathways between “upstream” determinants and exposures, and pathways leading from and affecting related health system interventions.

1.7.2 Research questions

Based on the above-described general aim and the specific focuses, we addressed the following research questions:

- RQ1) What health-endangering settings and practices do segregated Roma face and engage in over the long-term in Slovakia?
- RQ2) Why don't segregated Roma in Slovakia themselves do more for their health status?
- RQ3) Why don't healthcare frontliners in Slovakia do more for local segregated Roma?
- RQ4) How well do health-mediation programs address the determinants of the poor health status of segregated Roma?

Based on the findings from the studies on RQ1–RQ4 we also set out to answer and propose a guideline regarding the following question, to support clinical practitioners:

- RQ5) Do Roma and non-Roma patients need to be treated differently in clinical practice?

1.7.3 Thesis model

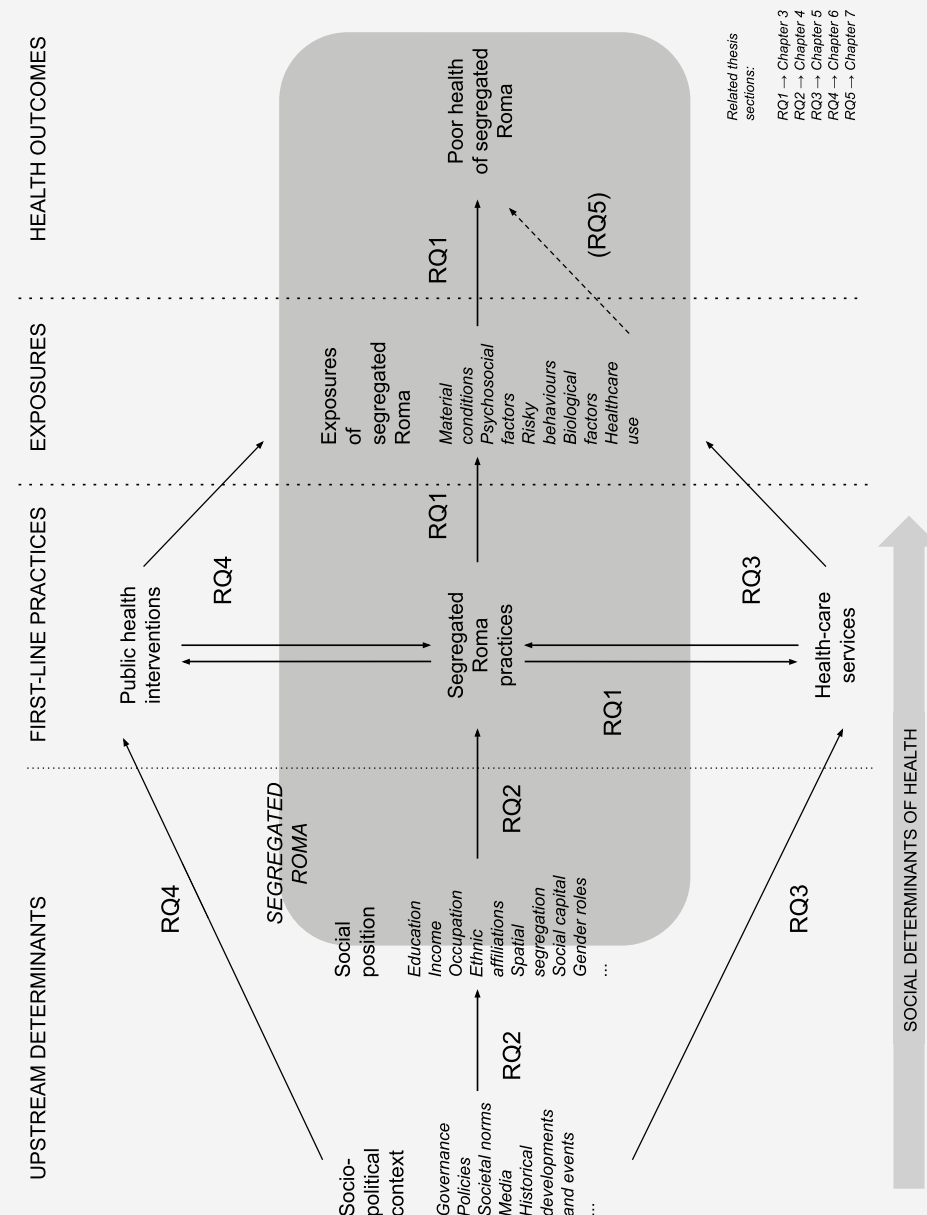


Figure 1.10 Thesis model

The expected and explored causal relations in the model are based on the WHO Framework on the social determinants of health (WHO 2010; see also Figure 1.4). For clarity, only relationships of the primary thesis' interests and no reverse effects expected, explored or found are indicated in the model.

1.7.4 Outline

In Chapter 2, we review the methods we used to answer the specific research questions. Chapters 3-7 are each devoted to one study dealing with one of the specific research questions. In Chapter 3, we focus on health-endangering settings and practices of segregated Roma in Slovakia (RQ1). In Chapter 4, we cover mechanisms supporting these Roma practices (RQ2). In Chapter 5, we move on to related frontline practices of the Slovak health system and focus on healthcare frontliners (RQ3). In Chapter 6, we evaluate the Slovak national health mediation program targeting segregated Roma (RQ4). In Chapter 7, we propose a guideline for clinical practitioners regarding Roma in CEE (RQ5). In Chapter 8, we discuss whether and how the findings regarding the specific research questions fulfilled the project's general aim.

Chapter 2

Methods

2.1 Samples

This thesis is based on four empirical studies regarding three samples (see Table 2.1 for a summary). For the first two studies, we obtained data from a single rural segregated Roma settlement with a population of approximately 260 people to assess exposures, health-related practices (RQ1; Chapter 3) and the mechanisms supporting health-related practices (RQ2, Chapter 4) within segregated Roma settlements in Slovakia. We then acquired extensive descriptive data on approximately 90 people from one extended family. Next, we visited for structured interviewing a sample of 10 of the settlement’s 48 households, representative for the settlement according to the households’ social ranking (low, medium and high) and affiliations to extended families. In these households, we interviewed 28 people, 22 of them adult women. In the follow-up observations and elicitations, we continued to consult with approximately 15 local Roma.

Table 2.1 Description of the samples for the studies included in the thesis

Research questions	Research period	Practices of	Final sample	Sample No
RQ1, RQ2	2004–2014	Segregated Roma	>120	1
RQ3	2013	Healthcare professionals	>40	2
RQ4	2014–2015	Health-mediation professionals	>100	3

In the third study, in order to assess Roma-related practices of healthcare professionals, we observed and interviewed 43 healthcare professionals from six different healthcare facilities in five different geographical locations who met Roma on a frequent basis (RQ3; Chapter 5). We did this in the two counties with the highest proportion of segregated Roma

communities in Slovakia. The healthcare professionals included hospital nurses and physicians who worked in gynaecology and obstetrics, paediatrics and internal medicine wards (31); emergency rescue assistants and physicians (10); and a nurse and a physician from a paediatric clinic (2). For the fourth empirical study, we used a sample of over 70 participants and 30 recipients of a national health-mediation program, in total covering over 200 segregated Roma localities in Slovakia. We did this to assess public health intervention practices targeting segregated Roma communities (RQ4; Chapter 6). The consulted program participants were people from varied locations and of varied organizational background: field-work frontliners and field-work coordinators and managers.

For the fifth study (RQ5; Chapter 7) no sample was needed.

2.2 Procedures and measures

The data acquisition for Chapters 3 and 4 (RQ1 and RQ2, sample 1) took place from 2004 to 2014. During the first year, we first opportunistically recorded direct observations, spontaneous declarations and replies in elicitation (ethnographic data) regarding approaches to health and exposures of the settlement's residents. Subsequently, we carried out structured in-depth interviews regarding the same topics in a locally representative sample of households. Last, over the next 10 years we kept returning for follow-up consultations regarding specific preliminary hypotheses and historical changes. To ensure comprehensiveness of the data according to clinical and public health recommendations, throughout all phases of data acquisition we used a related encyclopaedic source to guide the focus of our observations and elicitation in terms of topics (Sasinka et al. 2003).

The data collection for Chapter 5 (RQ3, sample 2) took place between April and September 2013, beginning with sampling the appropriate healthcare facilities. In the selected facilities we first job-shadowed (McDonald 2005) and informally interviewed selected healthcare frontliners to acquire ethnographic data on their practices and perspectives, subsequently analysed this data to formulate preliminary hypotheses, and then closed the data acquisition with follow-up structured interviews. In all phases, we focused primarily on capturing the nature and reasoning of the healthcare staff's practices regarding segregated Roma patients. In the last stage we additionally focused on the staff's resilience towards adoption of substandard practices – a theme emerging based on the preliminary analysis of the ethnographic data.

The data collection for Chapter 6 (RQ4, sample 3) took place between May 2014 and October 2015. It was designed primarily as a qualitative evaluation (Goodyear et al. 2014) of the studied national health-mediation program's agenda and implementation in terms of their appropriateness according to the World Health Organization's Framework for action on social determinants of health (WHO SDH Framework; Figure 1.4). After studying the program's documentation, we first acquired ethnographic data on the program's everyday practices across organizational levels (job-shadowing), as well as in the recipient localities (visits and stays), to assess the significance of the program in the everyday life of the varied consultants. Subsequently, we carried out interviews with the program's staff, structured according to the WHO SDH Framework. We finalised the data acquisition with follow-up interviews discussing preliminary findings regarding the study questions with selected staff members

2.3 Analyses

In all studies, our data consisted of written field-notes on direct observations and informal elicitation and of audio recordings from structured interviews. In all studies, we coded and analysed the merged field-notes and transcripts with respect to each of the studies' specific aims in the MAXQDA software, using either conventional or directed qualitative content analyses (Hsieh et al. 2005).



Chapter 3

Health-endangering everyday settings and practices in a rural segregated Roma settlement in Slovakia

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3.1 Abstract

Research into social root-causes of poor health within segregated Roma communities in Central and Eastern Europe, i.e. research into how, why and by whom high health-endangering settings and exposures are maintained here, is lacking. The aim of this study was to assess the local setup of health-endangering everyday settings and practices over the long-term in one such community. It is the initial part of a larger longitudinal study qualitatively exploring the social root-causes of poor Roma health status through the case of a particular settlement in Slovakia. The study, spanning 10 years, comprised four methodologically distinct phases combining ethnography and applied medical-anthropological surveying. The acquired data consisted of field notes on participant observations and records of elicitations focusing on both the setup and the social root-causes of local everyday health-endangering settings and practices. To create the here-presented descriptive summary of the local setup, we performed a qualitative content analysis based on the latest World Health Organization classification of health exposures. Across all the examined dimensions – material circumstances, psychosocial factors, health-related behaviours, social cohesion and healthcare utilization – all the settlements' residents faced a wide range of health-endangering settings and practices. How the residents engaged in some of these exposures and how these exposures affected residents' health varied according to local social stratifications. Most of the patterns described prevailed over the 10-year period. Some local health-endangering settings and practices were praised by most inhabitants using racialized ethnic terms constructed in contrast or in direct opposition to alleged non-Roma norms and ways. Our summary

provides a comprehensive and conveniently structured basis for grounded thinking about the intermediary social determinants of health within segregated Roma communities in Slovakia and beyond. It offers novel clues regarding how certain determinants might vary therein; how they might be contributing to health-deterioration; and how they might be causally inter-linked here. It also suggests racialized ethnically framed social counter-norms might be involved in the maintenance of analogous exposure setups.

3.2 Introduction

The Roma present the largest, internally most variable and traditionally most marginalized ethnically defined minority population in Europe. According to conventional social-scientific criteria, summing up of all the involved subgroups under one ethnically framed label “Roma” is problematic (Marushiakova et al. 2001; Stewart 2011). Despite their shared common ancient ancestry on the Indian subcontinent (Iovita et al. 2004), Roma subgroups show much greater variability in most tangible aspects, including e.g. their ethnonyms and mother tongues (Bakker 2012; Matras 2002), social organizations, customs, mutual relations (Marushiakova et al. 2001; Tcherenkov et al. 2004) and genes (Iovita et al. 2004; Martinez-Cruz et al. 2016), than subgroups of other ethnically defined European groups (such as the Dutch or the Slovaks). However, in their home countries the varied Roma subgroups constitute national Roma minorities, which alike occupy the lowest societal positions (e.g. attaining the lowest rates of employment, levels of education and income, the worst health status) (EUC 2004; EUC 2014; EUFRA et al. 2012) and which have historically faced and continue to face similar ethnically framed external pressures (e.g. discrimination, racism or outright antigypsyism) (Fraser 1995; Selling et al. 2015; Stewart 2012). Many social scientists claim that commonalities among the different Roma subgroups also involve similar ethnically framed ideologies and practices on their own part, albeit for the most part ones closely related to the external pressures mentioned (Gmelch 1986; MacLaughlin 1999; Stewart 2013).

As elsewhere in Central and Eastern Europe (CEE) (Cook et al. 2013; Hajioff et al. 2000), compared to the general population, the health status of Roma in Slovakia appears to be consistently poorer, too. The worst health outcomes are shown for physically segregated communities, home to approximately 40% of 450,000 Slovak Roma. For these places, numerous surveys claim worse self-rated health (e.g. Filadelfiova et al.

2012; Filadelfiova et al. 2007), demographic projections report higher mortality rates and a shorter life-span (e.g. Rosicova et al. 2011), and clinical studies show a significantly greater communicable and non-communicable disease burden across the life-course (e.g. Hasajova et al. 2014; Kolvek et al. 2012; Kristian et al. 2013; Rosenberger et al. 2014; Rudohradska et al. 2012; Sudzinova et al. 2013).

These segregated communities’ poor health outcomes seem to result from adverse circumstances therein. Higher smoking rates, less physical activity, riskier dietary habits and greater perceived healthcare access barriers have all been found in rigorous comparative studies (e.g. Babinska et al. 2014; Babinska et al. 2013; Hijova et al. 2014; Jarcuska et al. 2013). Other research indicates poor community and personal hygienic standards, a missing or dysfunctional basic infrastructure, increased environmental hazards, overcrowding and even food shortages (e.g. Berkesova et al. 2014; Rudohradska et al. 2012; Vazan et al. 2011). The only exceptions are findings debunking myths about higher alcohol consumption rates (Babinska et al. 2014; Kolarcik et al. 2010), greater promiscuity (Halanova et al. 2014), more adverse peer pressure (Bobakova et al. 2012) and dysfunctional social support (Bobakova et al. 2015; Kolarcik et al. 2012).

Research into the social root causes behind such and similar high health-exposures CEE Roma face is lacking. According to contemporary epidemiological theory (Dressler et al. 2005; Krieger 2011; Marmot et al. 2006), all steep ethnic health inequalities result from complex and, at least in part, historically unique social processes. Such inequalities form when varied actors contribute through their acts and everyday practices to systematically different health-endangering exposures in ethnically defined populations. The involved kinds of actors typically range from global, national and local authorities to members of the populations concerned, but their actual compositions and contributions are historically contingent and transient. In order to understand what could be done to tackle a specific ethnic health inequality, one thus also needs to study empirically how and why particular actors co-maintain specific related health-endangering exposures over the long-term – the social root causes of the inequalities. Such research is lacking in regard to CEE Roma (Cook et al. 2013; Fésüs et al. 2012; Hajioff et al. 2000; Reijneveld 2010).

For research into the social root causes behind any particular health inequality, qualitative case-studies focusing on the worse-off population’s health-endangering everyday settings and practices represent a good starting point. All disproportionate damage caused to the very bodies making up any worse-off populations happens exactly via the population members’ everyday settings and practices (Krieger 2005;

Here we present a study aimed at assessing the local setup of health-endangering everyday settings and practices over the long-term in a segregated rural Roma settlement in Slovakia. It is the initial part of a larger longitudinal study qualitatively exploring the social root-causes of poor CEE Roma health status through a particular case.

The fieldwork was carried out by the corresponding author. Acquired data consisted of field notes on direct participant observations and records of personal elicitations focusing on both the setup and possible social root-causes of local everyday health-endangering settings

and practices. To gain data specifically and exhaustively regarding all aspects considered to be health-endangering according to contemporary biomedical theory, throughout all phases of the study an encyclopaedic practitioner's handbook covering both clinical and public-health knowledge was being used to guide observations and elicitations (Sasinka et al. 2003).

3.3.2 Settings and samples

The south-central region of Slovakia was picked because of its historically high proportion of segregated Roma residents (Musinka et al. 2014). The single settlement used in this study, selected based on the socio-graphic survey, had a growing population of approximately 260 people (230 in 2004, 300 in 2014) – all self-declared Roma and speaking Romani as their mother tongue – compared to a declining population of approximately 530 non-Roma living in the rest of the village (580 in 2004, 470 in 2014). In 2004, approximately half of the settlement's inhabitants were children under 15 years old, and only 5 people were older than 60. For a concise overview of the recent history and variability of segregated Roma Settlements in Slovakia, see Scheffel (2004) and Musinka et al. (Musinka et al. 2014).

The sampling is detailed in Figure 3.1 and Figure 3.2. In the first ethnographic phase, most data obtained in the settlement was related to approximately 90 people belonging to one of the 3 then largest local fajti, i.e. specific transient kinship formations roughly overlapping with unilateral extended families (Kobes 2010). The systematic interviewing visited a sample of 10 households out of the settlement's total 48. The sample was representative according to the households' local socio-economic position (SEP), level of prestige, and affiliations to fajti. In the selected households, 28 informants were elicited, with 22 of them being adult women. Several other people participated in shorter sequences of the interviewing. Locally, men were considered less competent regarding health-related issues both by themselves and by women, and most of them also showed less interest in discussing health spontaneously. None of the people approached refused to participate in the interviewing. The closing follow-up observations and elicitations were limited to approximately 15 locals personally closest to the corresponding author.

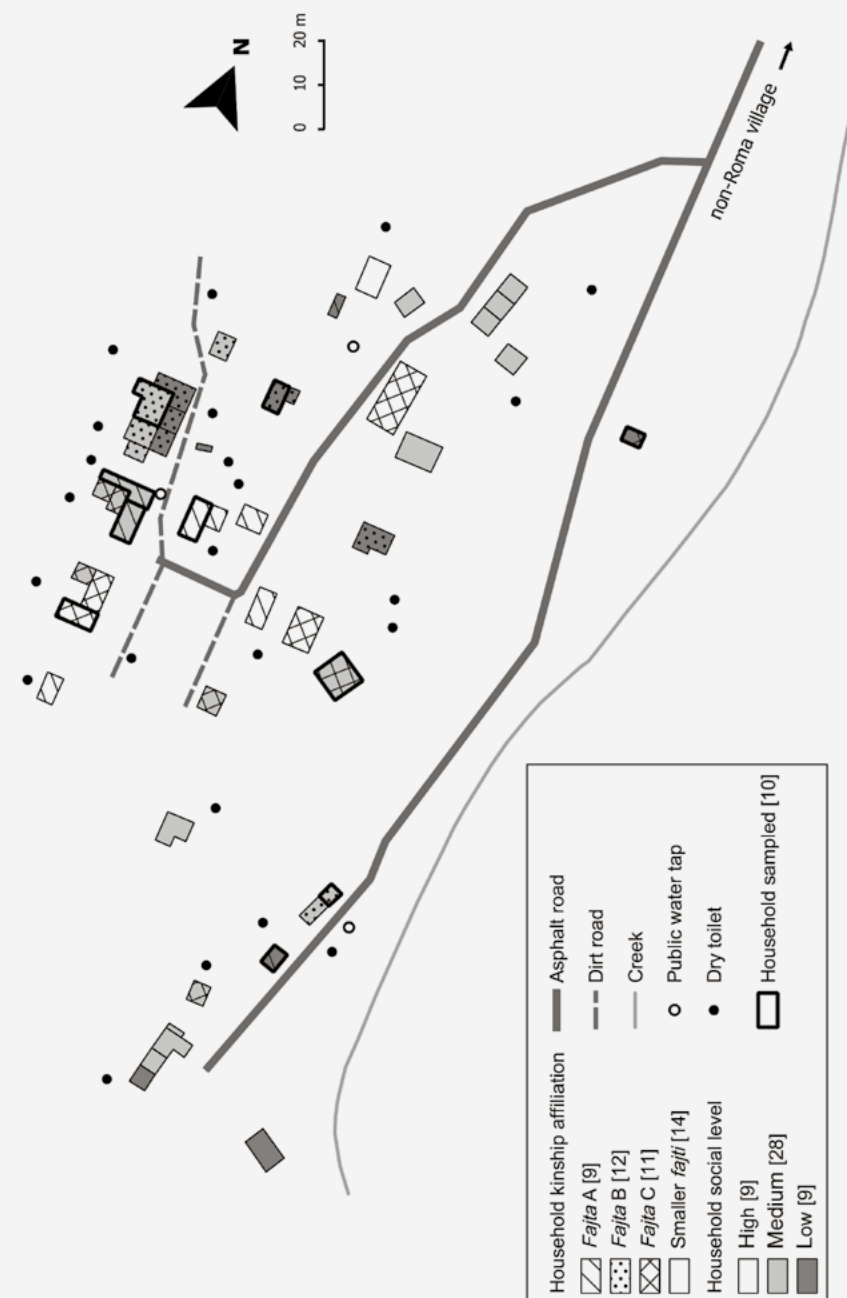


Figure 3.2 Map of the Roma settlement

Schematic map of the settlement also depicting stratifications used in the study; particular fajti refer to local Roma kinship formations (see main text for further details; courtesy of Zuzana Jarosova)

3.3.3 Procedure

The *socio-graphic field survey phase* consisted of personal inspection of all existing 11 rural segregated localities in the surveyed area. Local demographics, infrastructure, history, socioeconomic differences and inter-ethnic relations were assessed using brief questionnaires (see Annex 3.1). The particular settlement was selected randomly from the majority of examined localities that exhibited non-extreme characteristics in all surveyed respects: middle-sized enclaves older than five decades, physically and socially segregated, with substandard public infrastructure and apparent internal socioeconomic gradients.

The *initial ethnographic phase* consisted of establishing personal rapport with the local Roma, acquisition of proficiency in their primary language (a South-Central dialect of Romani) and in participant observation of their settings and practices. In this phase, the researcher's focus on the bio-medical aspects remained opportunistic and unsystematic.

The *systematic interviewing* was carried out using a bilingual template of implicit topics covered by several hundreds of questions in local Romani dialect, with particular questions focusing on elicitation of the locals' perspectives on the local setup and the social root-causes of particular local health-endangering settings and practices. The direction and sequence of questions for each particular topic were identical and analogous to the logic of elicitation proposed by Arthur Kleinman and widely used in clinically applied medical anthropology to construct 'illness explanatory models' (Kleinman 1980; Kleinman et al. 2006). Particular topics were adopted from the practitioner's guide (Sasinka et al. 2003). Wording was prepared with a close local informant. Interviewing differed considerably between households in detail and depth within a length range from several hours to several days per interview. The corresponding author's rather specific position of a friendly outsider and a supposed health expert allowed him to interview adult women intimately despite being an unrelated adult male – i.e. exceptional, according to strict local gender norms. Answers to questions were recorded in writing with a focus on capturing parts considered directly relevant to the particular questions and the specific Romani expressions used. Stratifications of households used in the sampling of households (see Figure 3.1 and Figure 3.2 for details) represented the consensus of several local informants regarding the particular households' SEP (*barvalipe* = affluence; associated with possession of amenities), level of prestige (level of ascribed *gizda* = snobbery), and affiliations to extended families (*fajti*).

The *follow-up ethnographic communication* was carried out through visits of the settlement regularly until late 2010, ranging from several days to several months in length. Until late 2014, regular follow-up

elicitations continued with the locals over the phone and in person outside the settlement. In addition to written field-notes on observations and informal elicitations, semi-structured in-depth follow-up interviews were organized and recorded by the corresponding author on several occasions.

3.3.4 Coding, analysis and reporting

To summarise the study findings on the local setup of health-related settings and practices, we coded and analysed selected study data as described in detail below. To ensure comprehensiveness and convenient intelligibility of the summary, especially for public health practitioners, we based the analysis on the latest World Health Organization (WHO) classification of known health-exposures, defined under the notion of 'intermediate social determinants of health'. The classification comes from a widely used theoretical framework, the WHO Framework on action for social determinants of health (WHO 2010a), compatible with our theoretical premises regarding the social root-causes of health inequalities cited in the Background.

We coded and merged all types of data from all sources and phases of the research as follows. We first coded any sequences of field notes considered relevant regarding the local setup of health-endangering settings and practices as such. Field notes from the initial ethnographic phase and from the follow-up ethnographic communication were coded manually, while transcripts of audio recordings from the late interviews were coded using the MAXQDA® software. To these sequences of text, as well as to those parts of the systematic interviews explicitly covering analogous themes, we then ascribed further hierarchical codes to distinguish data sequences relevant for particular domains of exposures and for their core elements, as defined in the guiding WHO source (WHO 2010a). In parallel to all these sequences of text, we also assigned codes denoting their relevance regarding the following variables: SEP (codes for 'rich', 'common' and 'poor' households), level of prestige (codes for 'snobby', 'normal' and 'squalid' households), affiliations to dominant *fajti* (codes for families 'A', 'B', 'C' and 'smaller *fajti*'), and time period (codes for 'first three years', 'mid-period' and 'last three years'). The same sub-coding was also applied to the selected relevant parts of the systematic interviews. As the levels of SEP and levels of prestige factually equaled – e.g. the households ascribed highest socioeconomic position were also ascribed the highest level of prestige – upon coding we eventually merged these two variables into one entitled 'social level'. This variable had three levels – high, medium and low – each indicating

the levels of both SEP and prestige ascribed to particular households (see also Figures 3.1 and 3.2).

We then performed qualitative content analysis, combining all coded data from the field notes and the relevant data from the systematic interviews, i.e. on health-endangering settings and practices. As a method for content analysis we used recurrent abstraction (LeCompte et al. 2013). This means that we repeatedly read and in steps summarized all text sequences on the endangering settings and practices that the locals faced and on how they engaged with them, regardless of their original source. Upon summarizing, we focused mainly on capturing the variability and dominant trends in local health-endangering settings and practices. For each intermediary determinant, we first created descriptive summaries regarding its particular core elements for particular social strata. We then cross-compared these summaries for estimations of major differences according to social level. To assess variability with respect to distinct age, gender and family-affiliation groups as well as with respect to time periods, notes were taken during the process of re-reading and then summarized for each domain of social determinants separately.

Based on the above-described analysis, we report on the local setup of health-endangering settings and practices across the following intermediary social determinants of health, as defined in the WHO source (WHO 2010a): material circumstances, psychosocial factors, health-related behaviours, social cohesion and health-system interactions. For each, we present dominant local trends regarding particular core elements. To these observations, we add notes on related variability according to social level, age, gender and research periods (no variations were found across fajti). We used bold text to point to particular core elements of the discussed intermediary determinants. To support the thus constructed findings with original data, in Tables 3.1-5 we include related illustrative quotes by local consultants. The quotes were selected based on two criteria: 1) they compactly illustrate our findings regarding particular exposures in the locals' own wording, and/or 2) they compactly illustrate on what kind of utterances we base our observations, suggestive of the locals' racialized ethnically framed reasoning. (See also Annex 3.2 Fieldwork visual reference for illustrative photographs.)

3.4 Results

3.4.1 Material circumstances

The majority of *houses* in the settlement were built illegally and maintained in a provisory way using unsuitable materials such as industrial landfills waste. Most houses sheltered several separate households in improvised extensions of the original buildings. Typical *internal housing conditions* included over-heated and damp air (locals' comfort zone was in the upper 20s°C and most houses were not ventilated regularly), cold walls (no insulation) and overcrowding (rooms sleeping up to five people were common).

Most households lacked basic *household infrastructure*. Only two households had indoor running water. For both heating and cooking, raw wood, illegally harvested from surrounding forests, was being burnt in second-hand iron stoves. Most households were connected to electricity, but many only through illegal extensions via other households. Several households used reclaimed car batteries instead. Only one nuclear family possessed a bathroom. Everybody used self-built outdoor dry toilets, with most children up to six years old defecating in public spaces. Basic *amenities*, such as refrigerators, washing machines, audio-visual entertainment equipment and cars, were popular and common in the settlement but usually limited to second-hand items which did not work and were not used as intended by the manufacturers. 'Strong' hi-fi equipment and cars in particular were praised and preferred as 'Gypsy' features.

Apart from the electrical network, *community infrastructure* consisted of one asphalt road connecting the settlement to the nearby village, several dirt roads and three outdoor sources of cold potable water. For liquid-waste disposal, households with running water used improvised drainages out to public spaces; others used the surroundings of their houses. Solid waste was being burnt in public places, disposed of at improvised landfills on the outskirts of the settlement or in open industrial containers provided and occasionally emptied by the municipality.

Related *direct health-risks* included: regular health and safety incidents within households (e.g. roof implosions, leakages, fires, window breakages); unhealthy household climates; frequent electricity outages and occasional injuries from improper handling of equipment; lack of personal-hygiene means, the presence of parasites (e.g. lice, fleas) and frequent intestinal infections; contamination of public space by urine, faeces and smoke, the presence of rodents; constant ergonomic strain. Related *social and economic tolls* included: stigmatization outside the settlement (due to e.g. smell, parasites, dirty clothes, outworn equipment)

and frequent relatively high-cost breakages (due to e.g. high-input and short working life of the outworn equipment).

The highest-ranked households occupied old, legally built former peasant houses, possessed amenities in better condition (e.g. registered cars, chainsaws, DVD-players), and paid more attention to tidiness outside their households (e.g. possession of a waste bin, children using dry toilets).

Over the 10-year research span, some material aspects improved, especially for those holding higher social positions. Several highest-ranked households insulated their houses; two bought new washing machines; most families originally in the possession of a car (some medium and all high social level households) kept renewing their second-hand fleets; several high and medium social level families purchased reclaimed computers, and even the poorest families were able to start using newer models of second-hand mobile phones. The lowest-ranked households experienced little or no improvements, with some experiencing further decline (e.g. moving from a deteriorated self-built wooden shelter to a smaller reclaimed wagon).

Table 3.1 Material circumstances quotes.

Quotes illustrating our findings regarding local health-endangering settings and practices (primarily material circumstances related), and the local consultants' related ethnically framed reasoning. In the adjacent column we list the exposure elements discussed.

Quotes	Exposure elements
<i>'I wish they [own children] would have more money than us... Why? So they're not down like us, so they don't have to steal wood, recycle metal.'</i> A., woman, 34, low social level [Sep 2005]	Household infrastructure; SEP
<i>'Do you know why Roma have always preferred the Žigulis over the Škodas [car brands]? Because of their acceleration! A Gypsy needs his engine to roar, you know what I mean?'</i> Z., man, 37, medium social level [Jul 2005]	Amenities
<i>'Of course it could be from the water [frequent diarrhoeas]. You've seen how we pulled water towards M's house. It's the same as with electricity and everything here. You want a new connection? You make it yourself [laughing]. [AB: But don't at least the local public water taps get checked for quality? I asked around and they do this regularly in the village.] C'mon, nobody like that [public health authorities] would ever come up here.'</i> S., man, 32, medium social level [Sep 2005]	Household infrastructure; Community infrastructure; discrimination
<i>'What's there not to like about it? [about rubbish in public spaces] This is normal here. We are Gypsies [sic] so we live like Gypsies. [...] You don't have to eat from the ground!'</i> M., woman, 36, high social level [Jun 2010]	Community infrastructure
<i>'Ok, they [the municipality] built this road here back then. When you are in need of Gypsy votes [for the mayor elections], everything is possible! But imagine you live back there [in the part of the settlement not connected to the asphalt road] like P. [low social level cousin]. No matter what you do, once it rains, you're all mud. And now go and visit the paediatrician.'</i> K., man, 48, medium social level [Jul 2010]	Community infrastructure; social tolls; healthcare use

3.4.2 Psychosocial factors

In terms of *longer periods of stress*, the locals appeared to suffer the most from their nuclear family members' detachment due to hospitalization, work trips or incarceration, and an effort was made to prevent such scenarios. Another long-term stressor was the terminal stages of terminal diseases in related elderly. The locals perceived the following in particular as the most frequent *incidental stressors*: a total lack of funds (i.e. fluctuating periods of literally no cash and no subsistence opportunities for the coming several weeks), visits outside the settlement beyond the nearby village (approximately weekly trips to the local administrative centre) and incidents of physical violence (approximately monthly involvement in fights within the settlement, mostly due to jealousy or conflicts of interests amongst *fajti*, culminating during celebrations after welfare payments).

Based on assessments of local informants (including non-Roma villagers), the settlement's Roma inhabitants had a radically lower *socioeconomic position (SEP)* compared with non-Roma living in the nearby village. Only one man in the settlement was long-term employed (as an industrial-construction worker), while most others worked only seasonally (and mostly illegally while formally unemployed) as occasional labourers, typically in construction or agriculture. A few high-ranked Roma women worked as unqualified helpers either in agriculture or (in latter periods) in services. The regular income of most Roma families depended on social-welfare payments, recycling (mostly of scrapped metal), and in the case of the lowest-ranked households also on gathering, hunting (e.g. mushrooms, fish), and petty thefts (poultry, cigarettes, cash). Several older higher-positioned Roma people held apprenticeship certificates acquired during the Communist era, and several younger people were studying to earn one, too. Most people, however, dropped-out of all formal-education trajectories early, and the majority had only finished compulsory elementary-school attendance.

Perception of own low SEPs (both within the settlement and in comparison, to local non-Roma) did not appear to cause the locals any stress. The low SEPs nevertheless remained causally linked to the frequency of a total lack of funds, which was considered an incidental stressor. Common *experiences of racism and discrimination* (e.g. preferential treatment of non-Roma in GP waiting rooms or withdrawals of employment opportunities upon arrival in person) were considered unjust but 'normal' and not stressful unless overtly offensive.

We identified the following local *strategies to prevent and cope with stress*. These were solidarity within *fajti* in cases of food shortages, serious health issues and violent incidents; solidarity beyond *fajti* where

children were at serious risk (e.g. rides to the hospital) or in conflicts with non-Roma (e.g. side-taking in fights); travelling only in groups pretending ostentatious confidence (e.g. loudness, strict speech-tones); avoidance of persons and institutional venues with a racist track-record; and drawing self-assurance from adherence to social norms framed in ethnic terms ('Gypsy' / 'Romani') constructed and praised mostly in contrast or in direct opposition to alleged non-Roma norms. The above strategies were not being interpreted by the locals themselves as such.

The local ethnically framed social counter-norms included e.g. specific work ethic (stressing the importance of the Roma ability to improvise in contrast to the non-Roma ability to bear drudgery), a specific kinship ethic (stressing e.g. different concepts of discretion and openness between generations), aesthetic style (e.g. relatively expressive 'Gypsy' clothing patterns and festive verbal communication), etc. The appropriateness of the locals' adherence to the particular norms was often argued by them using racialized arguments quoting specific related 'natural' Roma capacities embodied via their 'blood', 'brains', 'bodies', 'genes', etc. The same or analogous reasoning and argumentation was commonly used in local discussions (i.e. also beyond the discussions with the researcher) of most local practices (for examples from other domains see other sections of Results and Tables 3.1-5).

Across local social strata, the only variability in any of the above concerned that higher-ranked people experienced more stress regarding financial difficulties projected over longer periods (e.g. related to pension plans). Moreover, some practices necessarily associated with the maintenance of a higher SEP, such as compliance with rules in education, long-term employment, etc., were generally considered and ridiculed locally as being 'too non-Roma-like' (*gadjikano*). This posed an extra psychosocial dilemma for locals of high social level. In turn, lower-ranked people were generally considered and respected as more 'true Roma' (*prave Roma*). Over the last five years of the study period, a general lack of means of subsistence seemed to become more severe and continuous (constantly decreasing seasonal, unqualified and unregistered employment-opportunities; decreasing welfare payments; increasing formal requirements for employment; increased indebtedness by commercial lenders). This shift was also quoted as the sole reason for alleged local dramatic increase in the use of prescription tranquilizers and antidepressants in the settlement.

Table 3.2 Psychosocial factors quotes.

Quotes illustrating our findings regarding local health-endangering settings and practices (primarily psychosocial factors related), and the local consultants' related ethnically framed reasoning. In the adjacent column we list the exposure elements discussed.

Quotes	Exposure elements
'I am never-ever going to sit there on behalf of Fat Face again [crying, talking about a humiliating experience from a municipal committee meeting chaired by the village mayor]. When I start talking there, you know, I cannot put my words together as well as the others. I know what I would like to say, but I just don't speak non-Romani as well as they do. And then the looks – look at the stupid Gypsy speaking...' M., woman, 31, high social level [June 2005]	Stressors; stress-coping and prevention strategies
'This is the hardest thing both for him [referring to husband and father of four away at a rehab stay] and us [his nuclear family and siblings]. We don't see him every day, we can only visit him now and then thanks to M [a better off sister]. He's among the non-Roma all by himself all the time. The terrible silence, the watery food. Oh, God, I really think it would be far better for all of us if he just stayed at home and drank himself to death here!' K., woman 43, medium social level [Jul 2005]	Stressors; stress coping and prevention strategies; bonding social capital
'[To us, enough money is] when you simply don't need any more of it... When I imagine I'd have to work all the time like some non-Roma... they just work and work like dummies, then they fear for their money... I only need what I already have... I would only like to have the same a bit more easily.' D., woman, 31, medium social level [Aug 2005]	SEP perception
'There's so many disgusting things you non-Roma do! I cannot imagine my daughter seeing me without pants. [...] Or look at how you don't fear anything, the dead, the pain [...] your hearts are made of stone.' M2, woman, 29, high social level [Jul 2010]	Stress coping and prevention strategies; bonding social capital
'I tell you why [many Roma nowadays visit psychiatrists for subscription medications]. Because these are the hardest times we've ever been through. It has never been this bad before. Everybody can feel nothing good is coming our way anymore. Women are afraid for their kids' future. [Seasonal] work for men is gone. We will now even be working for free [referring to a new unemployment law]!' S., man, 41, medium social level [Aug 2014]	SEP; SEP perception; healthcare use

3.4.3 Health-related behaviours

The majority of adult and teenage men and the greater half of adult women in the settlement were daily **smokers**. Teenage women and younger people were being discouraged from smoking by others and lacked finances to purchase cigarettes regularly. People preferred to smoke high-priced labels of cigarettes but usually could afford only hand-made tobacco cigarettes without filters. Adult women and teenage women smoked more privately and less often; in the lowest strata children of all ages smoked occasionally.

Similar age and gender patterns were present with respect to **alcohol consumption**. Above the lowest social strata, where binge drinking was somewhat more frequent (several times per month), daily drinking was only moderate for most of the month (a pint of beer now and then) with the exception of two alcohol-dependent persons. In most households, binge-drinking took place solely following monthly welfare-payments and at anniversary celebrations. Even here, however, drinking until loss of basic social skills (more common amongst non-Roma men in the nearby village) was being discouraged as inappropriate. Such celebrations included loud reproduced 'Gypsy music' and intense dancing. During the research period there were no other cases of **drug abuse** observed.

Promiscuity was being strongly discouraged by everybody with respect to adults and teenage girls. Promiscuity of young men was being encouraged and praised, however, especially in a direction outside the settlement, including engagements with non-Roma women. Beyond such rhetoric, most pre-marital sexual relationships appeared as local and opportunistic, with women and men sharing their experiences only privately and with both sexes allegedly having only occasional pre-marital intercourse. Marital adultery was supposed to be common (several incidents per life per person) but was heavily sanctioned (e.g. public beatings or temporary retreat/expulsion of spouse to his/her parents' house) and never admitted publicly. Higher-ranked families put more effort into preservation and display of a non-promiscuous history of their teenage girls.

As regards **consanguinity**, people typically tried to form couples across geographical distance, yet preferred partners from already related *fajti*. Several first-cousin marriages were thus tolerated, silently or stressing the families' distant residency. High and medium social level adult women often opted for **intrauterine devices** after conceiving several children. **Condoms** were not in use in the settlement.

The local **diet** consisted mostly of large portions of cereal-flour based meals (bread, home-made fresh 'Gypsy pasta' and regular pasta) combined with potatoes, rice, cheap meat (smoked sausages, poultry

and fatty pork), and cooked vegetables. Most people did not consume any fresh vegetables, fruits or nuts. On more prominent occasions (Sundays, celebrations), unhealthy foods such as roasted fatty pork-meat was served preferably. Whenever possible financially, i.e. mostly according to social level, children were constantly offered sweets and people were drinking high-sugar soft-drinks.

With the exception of winter months, when watching TV for several hours per day was common, most children and adults within the settlement engaged in strenuous *physical activity* throughout most of their days. Children were playing outdoors, men were busy with taking care of wood, repairs of all kinds (houses, cars, other amenities), and women with repetitive cleaning of households, washing of clothes, cooking and carrying around of children. In addition, most people frequently organized gathering and hunting hikes in small collectives for both additional subsistence and entertainment (collecting scrapped metal, picking mushrooms, harvesting corn or potatoes, catching crawfish). Given the lack of standard amenities for most activities in most households, all of the described physical activity was relatively *un-ergonomic* and often dangerous. With increasing social status, people could afford and readily invested more into amenities that made the respective activities more comfortable (e.g. purchasing second-hand chainsaws).

Table 3.3 Health-related behaviors quotes.

Quotes illustrating our findings regarding local health-endangering settings and practices (primarily health-related behaviors related) and the local consultants' related ethnically framed reasoning. In the adjacent column we list the exposure elements discussed.

Quotes	Exposure elements
<i>'Of course, I believe it's true [that smoking causes cancer]. So what? Nobody will ever make me stop anyway. A Gypsy [sic] will always only want to live like a Gypsy... this is his life, to have a little smoke, to have a little fun, to drink a little.'</i> S., man, 31, medium social level [Jun 2005]	Smoking; alcohol consumption
<i>'This is what being a Gypsy means, if it rains, you get wet, you work away, you won't quit and change [your clothes]. When you're finished, only then you can change... This is what we are used to... Sure, you catch a cold - but you get healthy again! When you're in the middle of something, just do it, you wash, you change, you eat only afterwards.'</i> K., man, 27, medium social level [Sep 2005]	Ergonomic strain; risk perception
<i>'Secretly, most women will have their fun before their wedding... [Interviewer: 'Don't they fear getting pregnant... since, you know, condoms are not used around here'] ...A fear of what, new children being born? And what's bad about that? When there's a child, there will be a family... Usually, the two youngsters would really mean it once they don't fear taking it this far. There are lots of families like that here and they live happily.'</i> Z., woman, 25, medium social level [Sep 2005]	Promiscuity; contraception
<i>'What is she [talking about own daughter] a whore to smoke this young? [...] And tell me where would they get money for that [talking about occasional smoking of young children in the settlement]?' S., woman, 30, high social level [Sep 2005]</i>	Smoking; SEP; social norms
<i>'Gypsies love meat, especially pork meat, everybody knows that. [...] And we hate thin food with no taste. The soups you eat, pure water!'</i> M2, woman, 27, high social level [Sep 2008]	Diet

3.4.4 Social cohesion

In most respects, **bonding social capital** within the settlement was restricted to *fajti* comprising of several dozens of people. Despite a simultaneous public performance of distance according to the ascribed levels of prestige (hierarchies running within particular *fajti*), within these local kinship networks solidarity was absolute: from sharing of or donating supplies to nuclear families in need, through constant reciprocity of small favours, to side-taking in violent conflicts. Across local *fajti* boundaries, relationships were mostly competitive and rogue (constant mutual monitoring, blackwashing, public provocations, ostentatious ignorance, feuds, etc.) with the exception of life-threatening incidents involving children or elderly or in conflicts with non-Roma outside the settlement. Both of these bonding-capital networks provided an important **welfare safety-net** with respect to frequent health-related crises (e.g. preventing hunger, and assistance with severe injuries).

Framed in kinship (within *fajti*) and ethnic terms (towards the non-Roma), the above described **social norms** on one hand encouraged and enabled the building of strong local-bonding networks and on the other contributed to the isolation of particular *fajti* from each other and of the whole community from the non-Roma. The second restriction made it difficult for the locals to accumulate any **bridging** and **linking social capital** through engaging in reciprocity with outsiders. The lowest-ranked families possessed almost no relationships with non-Roma (except for friendships with socially excluded non-Roma), while even the highest-ranked individuals managed to maintain only several informal personal ties with local non-Roma from the village and only exceptionally in various local offices (e.g. long-term friendships or regular barterers actively hidden from public by the non-Roma). The lack of bridging and linking capital meant the only resources the communities could rely on with respect to health were resources owned by the particular local *fajti*.

Table 3.4 Social cohesion quotes.

Quotes illustrating our findings regarding local health-endangering settings and practices (primarily social cohesion related) and the local consultants' related ethnically framed reasoning. In the adjacent column we list the exposure elements discussed.

Quotes	Exposure elements
'Yes, their house is cleaner [referring to a low social level household from a different fajta in comparison to her own brother's low social level household], that's true. But you can see it yourself, they're just so stupid... they will always be the lowest ones. I'd definitely rather eat in my filthy brother's house, at the Italian's [a nick-name], than at the Ds!' D., woman, 31, medium social level [Jul 2005]	Bonding social capital; social norms
'Now if I had a kid, anyone from up there [referring to more affluent people within the settlement] would help me to get it to the hospital, you know that. [...] Around here, I only know X [reviewing non-Roma acquaintances]; this guy living in his parents' house on his own. Sometimes, I'd go visit him and we'd drink together. He was in jail, too, you know.' J., man, 37, low social level [Sep 2005]	Bonding social capital; social norms; linking and bridging social capital; welfare safety net
'You know, if you want to understand what Gypsy means, you should really talk rather with people like J. [a low social level man living in a reclaimed wagon] or P. and his wife [a medium social level related family living in a self-made hut] – they are proper Gypsies. You have to take care the gadje [non-Roma] way if you want a kitchen like this, if you want a washing-machine like this.' M., woman, 34, high social level [Aug 2008]	Bonding social capital; Linking social capital; SEP; amenities
'I don't understand how you non-Roma can let your little children be treated in schools the way they are being treated there. Strangers yelling at them... all the boring stuff... and you have to sit there and sit silently forever. Roma kids are unable to go through that... your kids are different.' M., woman, 36, high social level [Mar 2010]	Bonding social capital; linking social capital
'[If their kids would grow-up at A.B.'s mother's house], it would still be the same for them, I think. Maybe some small things would change... for some time... but most of it would be the same. It's in our blood! You know how they say 'Gypsy blood' – you cannot change that, no matter what. [...] Our life is so much better, more colourful.' L., woman, 43, high social level [Sep 2014]	Bonding social capital; social norms; linking social capital

3.4.5 Healthcare utilization

Within the settlement, access to **healthcare services** differed along the social gradient. As elsewhere in Slovakia, services **availability** (the technical potential to deal with local health needs), **accessibility** (relative geographical distance) and **accommodation** (ability to meet the technical constraints of potential clients) met contemporary EU standards (i.e. at least since a major health reform introduced in 2006). Several general practitioners were available within a radius of some kilometres. There was a local hospital 15 km away with an emergency entry-point operating non-stop, and emergency-rescue teams were typically able to reach the settlement within 15 minutes of being called, as required by law. In households of lower social status, however, people experienced greater **affordability** difficulties. Most of the time, their members were incapable of paying for transportation and service-related complementary fees (e.g. purchase of prescription medications not fully covered by the national insurance plan). Only the highest-ranked people were able to visit the appropriate providers whenever they felt they should, though with periods when even they could not. Others would recourse to improvised home-healing or sometimes to inappropriate use of emergency services (e.g. emergency calls in cases of uncomfortable long-term stomach pain).

Actual use of healthcare services within the described affordability constraints was as follows. Regarding light transient diseases (*bežne nasvalipna*), all local people used available services and took medication whenever possible exactly as recommended. Regarding serious chronic and terminal diseases (*phare nasvalipna*), consistent following of clinical recommendations over longer periods was generally an exception. Analogous general **non-compliance** occurred also regarding preventative and recovery recommendations. Such non-compliance regarding serious chronic and terminal diseases contrasted with several local strong inclinations. Everybody in the settlement feared pain and death, often spontaneously describing such emotions as 'naturally' more intense in comparison with the non-Roma. All locals claimed interest in and made an effort to learn their diagnoses and related medical recommendations, especially regarding chronic and terminal diseases specifically. And all locals trusted local medical practitioners, especially in terms of the functionality of their medical know-how (often quoting also a supposed non-Roma 'naturally' superior capacity to 'deal with complicated matters'). This contrast was considered understandable based on its congruency with local understanding of 'proper (Roma) life', framed in ethnic and often racialized terms. E.g. the locals would spontaneously quote a 'natural Roma incapacity' for long-term attentiveness to one's health.

Despite evocations of 'nature' and biology ('Gypsy blood', 'Gypsy brains', 'Gypsy genes') in such claims, however, in practice such ethnically framed norms applied mostly to the adult population and did not apply to children (at all) and elderly (as strictly). In the cases of the latter, health care was being utilized without any normative restrictions.

People of higher social status tended to opt for use of healthcare services for lighter symptoms – some of which the lower-ranked people did not regard as health issues – and to engage in short-term attempts to follow medical recommendations also regarding severe diseases. Among people of lower social status, **knowledge** and interest in knowledge of **medical theory and recommendations** was much rarer. Instead, people were using either explanations and therapeutic procedures improvised de novo within nuclear families (e.g. treatment of syphilis with petrol) or therapeutic procedures analogous to those used among local non-Roma (e.g. folk herbal-medicine).

Table 3.5 Healthcare utilization quotes.

Quotes illustrating our findings regarding local health-endangering settings and practices (primarily healthcare utilization related) and the local consultants' related ethnically framed reasoning. In the adjacent column we list the exposure elements discussed.

Quotes	Exposure elements
<i>'Of course they [healthcare staff in the nearby administrative centre] treat non-Roma differently... but they don't do any harm to us.'</i> K., man, 27, medium social level [Sep 2005]	Discrimination
<i>'What's causing them, what's causing them [diseases in general]... bacteria, right? [A.B.: 'And what's that exactly?']... It's these miniature [sic] animals... They live in the body, there are lots of them there; they eat and they destroy you with it... at least this is how I saw it [in a TV documentary].'</i> D., woman, 31, medium social level [Sep 2005]	Medical knowledge
<i>'You bet I'd see the doctor more often [did she have more cash for public transport] with my kids at least [...] How would we take those [prescription pills]? We take them exactly as told [by the healthcare staff] sure, the way the hours are supposed to go [...] Are you crazy? You cannot just add more to what you should be taking, that could hurt you... or it just doesn't work then.'</i> A., woman, 34, low social level [Sep 2005]	Healthcare affordability; SEP; healthcare use; compliance
<i>'Most people here only make some effort [taking medications for chronic diseases] when they are in unbearable pain. A soon as the pain goes, they return to normal Gypsy life. [AB: What do you mean?] You know, we stop caring that much. You start smoking more, eating what you like and so on.'</i> D2., woman, 34, lived in a nearby town, visiting a high social level sister [Jul 2005]	Compliance; social norms; bonding social capital
<i>'We [the Roma] are like that. We cannot withhold pain. When we are in pain, we panic. But what can we do? [...] I have tried to stay off chilli food for some time. I took the pills [medications for oesophagitis]. But, see, even I am not enough of a gadji [non-Roma woman] to stay that serious all the time. I will bear for some time. But then I just say to myself, what kind of a life is this? So you will vomit, so what?'</i> M., woman, 36, high social level [Mar 2010]	Compliance; social norms; bonding social capital

3.5 Discussion

We conducted a longitudinal study aimed at assessing the local setup of health-endangering everyday settings and practices over the long-term in a segregated rural Roma settlement in Slovakia. It is the initial part of a larger longitudinal study qualitatively exploring the social root-causes of poor CEE Roma health status through a particular case.

We found that across all the examined dimensions – material circumstances, psychosocial factors, health-related behaviours, social cohesion and healthcare utilization – all the settlements' residents faced a wide range of health-endangering settings and practices. How the residents engaged with and in some of these exposures and how these exposures affected whose residents' health varied according to local social stratifications. Most of the patterns described did not change over the 10-year period. Our summary also conveys that some of the local health-endangering settings and practices were commonly praised by most inhabitants using racialized ethnic terms constructed in contrast or in direct opposition to alleged non-Roma norms and ways.

No other scientific studies of comparable depth have been published. However, all of our findings on material conditions, healthcare accessibility, health-related behaviours and living standards match what has been identified as typical for segregated settlements in Slovakia in the same period by non-governmental sociographic and sociological surveys (e.g. Filadelfiova et al. 2012; Filadelfiova et al. 2007). Regarding psychosocial factors, social cohesion and healthcare utilization, our findings concur with results from a rigorous locally published mixed-methods study carried out by Davidova et al. (2010). In their findings, too, most Roma did not regard low SEP as a stressor; associations between their SEP and self-reported health-related measures were weak; they declared their own health status and the healthcare services they used as acceptable and considered prevention unnecessary; and they viewed familial and local relations with other Roma as their sole resources regarding health.

Our more particular findings regarding specific health-endangering exposures are consistent with and add understanding to findings from related scientific quantitative studies conducted in Slovakia as well as from scientific qualitative studies conducted elsewhere in CEE. This concerns mostly e.g. the previous, then unexpected, findings for Slovakia of equal to lower alcohol-consumption (Babinska et al. 2014; Kolarcik et al. 2010), equal to lower promiscuity (Halanova et al. 2014) and equal to higher familial social support and life satisfaction (Bobakova et al. 2015; Kolarcik et al. 2012) in comparison with local non-Roma. In their qualitative study, conducted with Roma in Bulgaria and Hungary, Kelly et al. (2004) found patterns in sexual behaviour similar to those identified

by us. Using focus groups to discuss Roma difficulties with access to sexual and reproductive services in Albania, Bulgaria and Macedonia, Colombini et al. (2011), too, identified transportation costs and expenses not covered by national health insurance as important barriers.

While compatible with and clarifying some previous findings, our summary also conveys novel information regarding intermediary determinants of health in segregated Roma settlements in Slovakia and beyond. First, the summary provides examples of how particular determinants might vary within the settlements, especially according to social status (see e.g. the differences in perception of low SEP as a stressor). Second, it provides detailed examples of mechanisms by which selected determinants might be contributing to worse health status in the segregated settlements (see e.g. the juxtaposition of particular material circumstances and related health and safety incidents). Third, it demonstrates how specifically particular determinants might be causally inter-linked here (see e.g. the intersectional trade-off relation described between local strategies of coping with stress and local possibilities for acquiring linking and bridging social capital).

Although primarily focused on summarizing the local setup of health-endangering settings and practices, our summary also offers several interesting hints regarding the setup's possible social root-causes, i.e. regarding why and by whom some of its aspects might be co-maintained. First, it indicates that the found active participation of segregated Roma in the maintenance of particular health exposures might be supported by their broader ethnically understood specific social norms, preferences and tastes (consider e.g. the spontaneous ethnic framing of preferences of relatively well-off Roma for certain exposures). These social norms appeared to be conceived of, developed and maintained by the locals mostly in contrast or direct opposition to respective alleged non-Roma alternatives (consider e.g. the common spontaneous contrasting and down-playing of the 'non-Roma-like' ways). Moreover, the appropriateness of the locals' adherence to the particular norms was often argued by them using racialized arguments (consider e.g. quoting specific related 'natural' Roma capacities embodied via their 'blood', 'brains', 'bodies', 'genes', etc.).

Second, should the above indication of specific social counter-norms prove correct, it might allow formulations of novel structural constructivist (Dressler et al. 2005) explanations for various previously found surprising associations. E.g. confirmation of distinct understanding on the part of the Roma of their own health-needs, preferences and their own related capacities (see the described informed non-compliance with clinical recommendations within the higher-ranked households despite available required funds) could shed new light on the surprising

findings by Geckova et al. (2014) and Davidova et al. (2010) on the poor correlation between SEP and health-related measures within Roma settlements in Slovakia.

We believe that these two explanatory hints are especially noteworthy, as they suggest the currently discussed range of explanations regarding the persistence of high health exposures segregated CEE Roma face despite a long history of varied interventions (Barany 2002; Földes et al. 2012b) might be too narrow. According to their calls for further research, most engaged biomedical researchers seem to expect the health inequalities between CEE Roma and non-Roma might become fully explained by accounting for ethnic discrimination and social exclusion by non-Roma at the structural level, and for uninformed residual Roma traditions at the level of risky behaviours (e.g. Janevic et al. 2012; Kolarcik et al. 2009; Voko et al. 2009). Our material strongly indicates that at present in some segregated places a partly racialized ethnically framed active self-exclusion on the part of the Roma might be involved, too.

Historical origin, variability and means of reproduction of such or similar cultural resilience among segregated Roma and analogous groups across the continent is already long being debated in social scientific literature (e.g. Stewart 2013). Its presence has been realized and continues to be documented especially by ethnographers (e.g. Engebrigtsen 2007; Gay Y Blasco 1999; Okely 1983; Stewart 1997; Tauber 2006). But similar findings resonate also in most qualitative research relying on a consistent field-presence and/or more open-ended methods, e.g. in biomedical studies addressing analogous groups beyond CEE (e.g. Jesper et al. 2008; Van Cleemput et al. 2007) or in other local anthropological research (e.g. Podolinska et al. 2014; Skupnik 2007).

3.5.1 Strengths and limitations

The main strength of our study was its mixed-methods approach. The preliminary socio-graphic survey enabled identification of a relatively typical locality. The use of ethnographic methods enabled intimate access to local everyday settings and local people. The systematic interviewing across several local stratifications allowed accounting for local variability as well as for topical omissions in the previous less-systematic phase. The follow-up communication enabled detection of major changes in the observed phenomena over time and additional reflections of preliminary interpretations by local core informants. Choosing the WHO classification of social determinants of health as a template for analysis and reporting enabled direct public-health significance of our summary according to contemporary health inequality theories.

Our use of the research-design and our reporting also had some limitations. First, the field-work and most of the analyses were performed by a single researcher, limiting the potential for inter-personal corroboration. Second, although preceded by a careful selection of a place typical for the geographical area, the research examined only a single settlement. Third, it was impossible to remain personally embedded in the settlement for the whole course of the research. Lastly, the explicit focus of our summary on the description of local settings and practices limited the space for presentation of authentic reasoning of the people being described. While all these limitations appear to be well out-weighted by the good match of our findings with other literature, any generalizations of the clues our paper presents should only be attempted with due caution.

3.5.2 Conclusions and implications

Our summary might serve as detailed and conveniently structured sample material for grounded thinking about health inequalities within socio-logically analogous locations. It offers novel clues especially regarding which intermediary social determinants of health might vary therein and how; which of them might be contributing to health-deterioration and in what way; and how they might be causally inter-linked here.

Our findings also convey that the local preferences for some of the local health-endangering settings and practices were typically framed in racialized ethnic terms constructed in contrast or in direct opposition to alleged non-Roma norms and ways, as such. For public health practice, this indicates that within at least some segregated Roma settlements traditional biomedical interventions and recommendations might be less efficient than elsewhere and why. In cases where the presence of such social counter-norms would apply, the recent trend of designing and implementing public-health interventions using community-based participation may be especially appropriate. To explore this practically and ethically extremely intriguing possibility beyond the limitations of this descriptive summary, more research and analyses are needed focusing directly on the social-root causes of analogous Roma practices.

Our findings also confirm that a social-constructivist approach, i.e. one including a focus on the perspectives of the worse-off populations' members themselves as well as their broader socio-historical contexts (Dressler 2005; Frohlich et al. 2001; Krieger 2011), might offer a particularly productive possibility for researching social determinants of health in the case of segregated ethnic communities.

Annex 3.1 Sociography and questionnaire

Basic sociographic parameters ¹

How many people live in the village?

How many people live in the nearby Roma settlement?

How old is the Roma settlement?

Is the settlement physically segregated from the village? If so, how?

What is the situation within the settlement regarding:

- Water supply
- Heating
- Electricity
- Sewerage
- Waste disposal
- Roads

Are there any significant economic and infrastructural differences within the settlement?

How are the social relationships between the villagers and the Roma settlement inhabitants? Are there any restrictions in place in the village regarding the settlement's inhabitants?

Which general practitioners and pediatricians do the people in the Roma settlement visit?

Brief questionnaire for local healthcare professionals ²

Are you aware of any activities in place locally focused specifically on the health of the Roma?

Do you consider the health situation of local Roma settlement(s) to be specific?

If so, in what respects?

¹ The following basic sociography questions were administered by the corresponding author in person in the form of an informal structured interview seeking personal estimates. In all places, all of the questions were answered by at least one respondent working for the local municipality and one respondent living in the Roma settlement. In most cases, estimates were provided by several respondents. The answers were recorded in writing by the interviewer.

² The following brief questions were administered by the corresponding author in person in the form of an informal structured interview. The respondents were local public health officers (contacted through the network of Regional State Public Health Agencies), local general practitioners and local pediatricians cited in the answers of the previously carried-out sociographic interviews. The answers were recorded in writing by the interviewer.



Chapter 4

Why don't segregated Roma do more for their health?

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4.1 Abstract

The health status of segregated Roma is poor. To understand why segregated Roma engage in health-endangering practices, we explored their nonadherence to clinical and public health recommendations. We examined one segregated Roma settlement of 260 inhabitants in Slovakia. To obtain qualitative data on local-level mechanisms supporting Roma nonadherence, we combined ethnography and systematic interviewing over 10 years. We then performed a qualitative content analysis based on sociological and public health theories. Our explanatory framework summarizes how the nonadherence of local Roma was supported by an interlocked system of seven mechanisms, controlled by and operating through both local Roma and non-Roma. These regard the Roma situation of poverty, segregation and substandard infrastructure; the Roma socialization into their situation; the Roma-perceived value of Roma alternative practices; the exclusionary non-Roma and self-exclusionary Roma ideologies; the discrimination, racism and dysfunctional support towards Roma by non-Roma; and drawbacks in adherence. Non-Roma ideologies, internalized by Roma into a racialized ethnic identity through socialization, and drawbacks in adherence might present powerful, yet neglected, mechanisms supporting segregated Roma nonadherence.

4.2 Introduction

The poor health status of segregated Roma represents the steepest and most persistent health inequalities in Central and Eastern Europe (CEE). Roma make up one of the largest ethnically outlined populations in Europe (Crowe 2007; EUFRA et al. 2012) with current estimates ranging

up to 12 million persons and a presence in most CEE countries. Facing and adapting to an ongoing history of prejudice, discrimination and paternalist remedial policies, substantial proportions of Roma reside in poor segregated communities (EUFRA et al. 2012; Stewart 2012). Compared with the general population, these communities are at the lowest levels of education and income and have the highest rates of unemployment (EUFRA et al. 2012). Moreover, they carry the greatest burdens of both infectious and non-communicable diseases and have the shortest life-spans (Cook et al. 2013; EUC 2014).

Well exemplifying the situation elsewhere in CEE (Cook et al. 2013), the poor health-status of segregated Roma in Slovakia is also maintained through people's own everyday practices (EUFRA et al. 2012). Despite notable exceptions indicating equal or healthier social support (Bobakova et al. 2015; Kolarcik et al. 2012), alcohol and illicit drug use (Babinska et al. 2014; Kolarcik et al. 2010) and sexual behaviours (Halanova et al. 2014), rigorous studies show that overall Slovak segregated Roma engage in riskier health-related practices than the rest of the population. For example, higher levels of smoking (Belak 2013; Jarcuska et al. 2013), an unhealthier diet (Hijova et al. 2014; Krajcovicova-Kudlackova et al. 2004), unhealthier physical activity (Babinska et al. 2014; Kolarcik et al. 2010), the maintenance of riskier material conditions (Filadelfiova et al. 2012; Majdan et al. 2012) and less effective healthcare use (Belak 2013; Jarcuska et al. 2013) are found among these Roma.

The standard socio-epidemiological approach to explore the drivers behind health-related practices yields practically inconclusive results in the case of segregated CEE Roma. Studies focusing on the associations of health-related behaviours with measures of socioeconomic position (SEP) do not allow questions on why many more Roma live at the lower end of the existing SEP gradients or how such positioning results in more adverse health-related practices to be answered (Földes et al. 2012a; Reijneveld 2010). Expected associations often do not get confirmed here for all the proxies examined – segregated Roma seem to be doing at least some things differently or to different effects compared to low-SEP segments of the general populations (e.g. Geckova et al. 2014; Janevic et al. 2012; Kolarcik et al. 2009; Voko et al. 2009). Such a situation is common with ethnic health inequalities research in general (Dressler 2005; Smith 2000).

Insight into the driving forces behind the everyday health-endangering practices of CEE segregated Roma is lacking. To advance public health understanding of persisting health inequalities, a sociologically informed exploration of local-level drivers via perspectives of the target populations themselves has long been proposed as a promising starting point both in general (Garthwaite et al. 2016; Singer et al. 2016)

and with respect to ethnic health inequalities specifically (Dressler et al. 2005). Recently, several studies qualitatively exploring specific CEE Roma health-related practices have confirmed the expected negative influences of poverty, discrimination and racism (e.g. Andreassen et al. 2017; Janevic et al. 2011; Kelly et al. 2004). However, more comprehensive exploratory studies are still missing.

We therefore explored by way of a sociologically informed ethnographic study the local-level mechanisms that support segregated CEE Roma nonadherence to clinical and public health recommendations.

4.3 Methods

4.3.1 Theory

We used structural-constructivist relational theories of human action as the conceptual framework of our study (Archer 2000; Bourdieu 1998). According to these theories, everyday practices are driven mostly by the actors' practical reasoning, which is spatiotemporally contingent, partially implicit and subconscious, and significantly shaped by historically evolving structures and social constructions. The structures represent the environmental, social and bodily conditions in which the selected actors operate. The social constructions represent how the actors interpret these conditions. Actors acquire their specific practical reasoning gradually, through the process of socialization. In this process, the actors' bodies, inner drives, motivations and interpretative repertoires become practically attuned to their specific conditions. Both acting according to any reasoning in practice and specific socialization patterns continue to depend on enabling environments. What specific structures support which specific practices and how they do so can be best examined by exploring related social constructions that the specific actors use, i.e. their related practical reasoning and their socialization in such reasoning.

4.3.2 Settings and design

This study was part of a larger longitudinal study exploring the social root-causes of poor health status of segregated CEE Roma through the case of a segregated settlement in Slovakia. The larger study spanned 2004-2014 and consisted of four methodologically distinct

phases combining ethnography (Reeves et al. 2008) and systematic medical-anthropological interviewing (Hausmann-Muela et al. 2003): 1) a socio-graphic survey, aimed at the selection of a single segregated place; 2) ethnography, aimed at gaining close personal access to and extensive primary data regarding the local everyday health-endangering settings and practices; 3) systematic interviewing, aimed at increasing local representativeness of the collected material; and 4) follow-up communication, aimed at obtaining locals' reflections on preliminary interpretations and obtaining additional data on long-term outcomes. All fieldwork was carried out by the first author. All aspects of the larger study methodology, relevant also for this study, have been reported in more detail elsewhere (Belak et al. 2017a). This regards a description of the setting of the Roma in Slovakia, our procedure for selection of the locality and informants, the characteristics of the selected settlement, the observation and elicitation procedures that we used in all phases of the study, our initial coding of the study data, the first author's embeddedness in the settlement and the study's potential biases.

In the terms of the theories outlined above, the primary focus of this study was on what local structures supported the actors' eventual nonadherence to clinical and public health recommendations over the long-term (cf. Frohlich et al. 2001; Singer et al. 2016). Drawing on the theories, we started with an exploration of the reasoning of local Roma regarding nonadherence (cf. Cockerham 2005; Frohlich et al. 2001). Then, we explored what experiences contributed to the adoption of such reasoning (cf. Singh-Manoux et al. 2005; Williams 1995). Finally, we explored local-level mechanisms that supported both the adoption of such reasoning and the everyday practice of pro-nonadherence reasoning, i.e. the local structures that systematically enabled such adoption and such practices (Hedström et al. 2010).

4.3.3 Samples/Informants

In phase 1 (July 2004), we selected a single segregated settlement with a growing population of approximately 260 people (230 in 2004, 300 in 2014) on the outskirts of a village with a declining non-Roma population of about 530 (580 in 2004, 470 in 2014). In 2004, approximately half of the Roma settlement's inhabitants were children under age 15 years, and only 5 people were older than 60. In phase 2 (September 2004 – October 2005), we obtained data on approximately 90 people belonging to one of the three then largest extended families in the settlement. In phase 3 (October 2005), we visited a sample of 10 of the settlement's 48 households. The sample was representative according to the households' social ranking (low,

medium and high), based on the combination of ascribed affluence and prestige, and kinship affiliations (to the three largest extended families). In these households, we interviewed 28 people, 22 of them adult women. Locally, men were considered less competent regarding health-related issues both by themselves and by women, and most of them also showed less interest in discussing health spontaneously. None of the people approached refused to participate in the interviews. Phase 4 follow-up observations and elicitations (November 2005 – November 2014) were limited to approximately 15 Roma personally closest to the first author.

4.3.4 Procedure

The data consisted of field notes on direct observations and written and audio records of elicitations obtained during phases 2-4. We collected observations, spontaneous declarations and replies in elicitations regarding: why individual Roma did not adhere to selected clinical and public health recommendations – as data on reasoning for nonadherence; what experiences individual Roma considered important for their adoption of such pro-nonadherence reasoning – as data on the adoption of pro-nonadherence reasoning; and how and what local circumstances supported the recurrence of such contributing experiences and non-adherence practices – as data on local-level supporting mechanisms.

To gain data specifically and exhaustively on contemporary clinical and public health recommendations, an encyclopaedic practitioner's handbook covering both clinical and public health knowledge and recommendations was used throughout all phases of the study to guide observations and elicitations in terms of topics (Sasinka et al. 2003).

4.3.5 Coding, analysis and reporting

For coding the data we re-used transcripts from previous analyses (Belak et al. 2017a). In these transcripts, all field notes and audio recordings relevant regarding health-related settings and practices were already merged and coded for relevance in relation to household social levels, kinship affiliations, genders, ages, time periods, and domains of exposures and their core elements, as defined in a widely used eco-social framework on social determinants of health (WHO 2010a). The first author then in steps added new axial codes signifying "pro-nonadherence reasoning", "experiences contributing" to the adoption of such reasoning and local-level "mechanisms".

Next, we performed a qualitative content analysis using recurrent abstraction (LeCompte et al. 2013). We repeatedly read and in steps summarized all text sequences coded as relating to pro-nonadherence reasoning, experiences contributing to the adoption of such reasoning, and local-level mechanisms. We focused on capturing local variability and the most salient kinds, as follows. First, we summarized sequences on local reasoning, yielding 13 kinds of reasoning. We have reported these in Annex 4.1. Second, we summarized sequences of experiences contributing to the adoption of pro-nonadherence reasoning, yielding four such kinds. We have reported these in Annex 4.2. Then, we summarized sequences on local mechanisms, yielding seven mechanisms in total. We report these mechanisms in our results below. During this analysis, we realized that some of the mechanisms were controlled by and operating through Roma actors in the settlement, while others more by local non-Roma actors outside the settlement. We report according to this distinction, as it informs on which actors need to be prioritised in interventions and regarding what mechanisms.

During the analyses, we also realized that the identified mechanisms supported each other. Given that most of the identified individual mechanisms have been previously described with respect to CEE Roma (see Introduction), we focused mainly on reporting their mutual inter-relations. For more information and illustrative examples, we refer the reader to Annexes 4.1, 4.2 and 4.3 and to our previously published detailed descriptive report on other parts of the same study (Belak et al. 2017a).

4.4 Results

We identified seven local-level mechanisms that supported the adopting of pro-nonadherence reasoning by Roma and their nonadherence practices. Below, for each of these mechanisms we first briefly describe their underlying structure and then list and illustrate how they worked (for further details and illustrations, see also Annexes 4.1, 4.2 and 4.3). In the last section, we describe how these mechanisms mutually supported each other.

4.4.1 *Mechanisms controlled by and operating through local Roma*

Roma situation of poverty, segregation and substandard infrastructure

The Roma settlement was trans-generationally extremely poor, segregated both socially and physically from the local non-Roma village and had substandard infrastructure. This directly supported the adopting of pro-nonadherence reasoning by Roma youth, as it contributed to their frequent failures of adherence, and because some aspects of the setting were experienced by the youth as significantly positive. For instance, when trying to adhere to medication advice, young families experienced an inability to cover costs of medications due to low income, to understand clinical recommendations due to substandard education, to preserve documentation on their diseases due to a lack of personal storage space, etc. Yet, to illustrate their perceived positive experience of this setting, young people found that the segregated housing setup (yards shared by extended families outside the non-Roma village) enabled convenient child supervision (no contact with strangers or car traffic, etc.).

The setting directly supported nonadherence practices via a constant lack of means for adherence and a constant availability of means for local alternatives to adherence. Except for the highest ranked families, Roma lacked the income, information and infrastructure necessary to maintain 'outside' (i.e. non-Roma) standards of personal healthcare (hygiene, safety measures, healthcare services access, etc.). Meanwhile, the substandard infrastructure and spatial segregation enabled unhealthier ways of provision of e.g. heating (wooden stoves, proximity of forest), water, electricity (unsafe illegal connections) and waste disposal (un-sanctioned garbage piles).

Roma self-exclusionary ideology and misinformation

The dominant views in the settlement claimed the general or relative (compared with adherence to local alternatives) inappropriateness for Roma of adherence to alleged outside standards. Such inappropriateness was typically framed in racialized and gendered ethnic terms quoting outdated racist expert concepts. This directly supported Roma youth in adopting pro-nonadherence reasoning by presenting appealing interpretations of standard local experiences with adherence failures, adherence and nonadherence. For example, youth interpreted some of the adherence failures they experienced as being due to their personal incapacities (e.g. by their strong negative feelings regarding most aspects of hospitalization) as results and proofs of “natural Roma / Gypsy” collective bodily incapacity, quoting allegedly specific Roma biology (Roma genes, blood, brains, etc.).

Roma socialization for their situation

Based on experiences and dominant local interpretations of them, youth in the settlement gradually adopted practical reasoning that favoured local alternatives over outside standards. Adoption of pro-nonadherence reasoning formed an integral part of this contrastive mode of socialization: youth lacking appropriate means to adhere and being exposed to dominant local self-exclusionary views and misinformation gradually resigned and became adults who lacked the means and motivation needed to adhere. The socialization directly supported local nonadherence practices by generating adults prone to practice and further develop rather local alternatives to adherence regarding their health problems in general.

Roma alternative practices

Most adults in the settlements appraised, practiced and developed standards understood as more appropriate alternatives to alleged outside standards. The better appropriateness of such standards for Roma was typically framed in racialized and gendered ethnic terms in line with local self-exclusionary ideologies. Relatively riskier health behaviours and a less attentive approach to their own health formed an integral part of such alternative practices.

This approach directly supported Roma youth in adopting pro-nonadherence reasoning by generating direct negative experiences with pro-adherence experiments and positive experiences with Roma alternatives to adherence. For example, youth witnessed their parents’ frequent failures to adhere to clinical recommendations. Simultaneously, they experienced some aspects of Roma alternatives to clinical recommendations as advantageous (e.g. compared to institutional care,

they viewed homecare in the case of treating alcohol dependency as providing comparable health effects and better social side-effects; see also Annex 4.3).

4.4.2 Mechanisms controlled by and operating through local non-Roma

Non-Roma anti-Roma ideologies and misinformation

Local non-Roma typically lacked information regarding most aspects of everyday life in the Roma settlement and expressed beliefs that Roma were naturally unable to maintain non-Roma standards. To support the latter, they quoted outdated expert concepts and personal experiences with deliberate Roma nonadherence practices. Such perspectives mostly supported Roma youth and early adolescents in adopting pro-nonadherence reasoning indirectly, by inspiring Roma self-exclusionary ideologies. Such views also indirectly supported Roma alternative practices via consequent non-Roma discrimination, racism and dysfunctional support for Roma (see below).

Non-Roma discrimination, racism and dysfunctional support towards Roma

Local non-Roma often acted towards the Roma in a discriminatory and racist manner. Moreover, even sincere local non-Roma attempts to provide support to Roma, typically drawn implicitly on racist or otherwise misinformed concepts, usually lacked practical functionality. Such approaches directly supported the adopting of pro-nonadherence reasoning by Roma youth by contributing to their experiences of related adherence failures. Examples of discrimination are that the Roma youth experienced longer waiting times as well as racist slurs from personnel. An example of dysfunctional support is that a public hygienic centre was installed in the settlement by the local municipality without consulting the local Roma. It then went ignored by the Roma community because it was impractical and ugly.

Drawbacks in adherence

The restrictive aspects of clinical and public health recommendations were mostly considered by the Roma as inherently conflicting with a “good life”, typically framed in racialized and gendered ethnic terms in line with the dominant local Roma self-exclusionary ideologies and misinformation. Such aspects directly supported Roma youth in adopting pro-nonadherence reasoning by labelling adherence as disadvantageous. For example, Roma youth found some clinically successful experiments

with adherence (e.g. proper management of chronic diseases via dietary restrictions) to lead to too significant losses in terms of the quality of life that “real Roma” could and should prefer.

4.4.3 An inter-locked system of local-level mechanisms

The identified mechanisms formed an inter-locked system, as schematically summarized in Figure 4.1.

Mechanisms controlled by and operating through local Roma

The Roma situation of poverty, segregation and substandard infrastructure directly supported Roma self-exclusionary ideologies and misinformation by generating a lack of experience with and information on outside standards. For example, the Roma were unaware that racist expert theories about Roma “natural incapacities” were outdated. They further lacked experience in how under different circumstances some adherence practices can become compatible with high-quality life according to their criteria. This setting also directly supported non-Roma anti-Roma ideologies and misinformation. For instance, due to segregation, non-Roma locals lacked experience and information on the efforts that Roma had to make regarding personal healthcare and the constraints that they faced.

Roma socialization for their situation directly supported the Roma self-exclusionary ideology and misinformation by raising adults who contributed further to the trans-generational transfer of such perspectives. For example, adults would mock and ridicule youth experiments with adherence as “too non-Roma like”, “unnatural for Roma”, “too feminine”, etc.

Roma alternative practices directly supported the Roma situation of poverty, segregation and substandard infrastructure, as they included the active maintenance of existing settings. For instance, adult Roma kept investing in and repairing the substandard local infrastructure. Roma alternative practices also directly supported the non-Roma in maintaining their anti-Roma ideologies and misinformation, as the non-Roma frequently observed deliberate Roma failures to adhere (e.g. apparently deliberate Roma withdrawals from life-saving clinical plans).

Mechanisms controlled by and operating through local non-Roma

Anti-Roma ideologies and misinformation among non-Roma directly inspired the self-exclusionary ideologies of Roma. For instance, in their own racialized explanations of Roma nonadherence, Roma would often quote the racist “expert” views of non-Roma. Such perspectives also

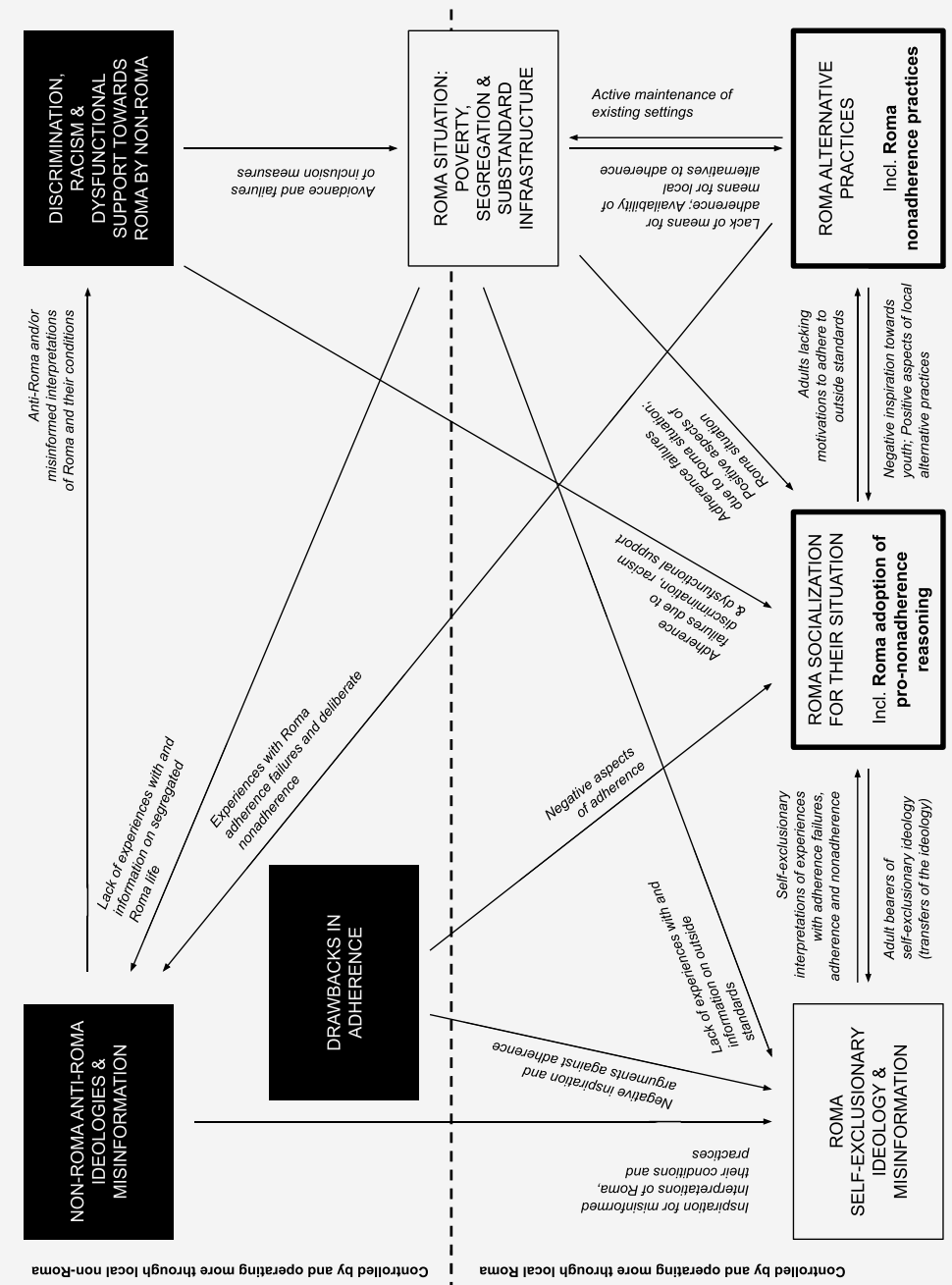


Figure 4.1 Local-level mechanisms supporting segregated Roma nonadherence reasoning and practices (Slovakia 2004-2014)

directly supported non-Roma discrimination, racism and dysfunctional support, as they provided a seemingly reasonable rationale for such practices. For example, local non-Roma professionals would often quote misinformed knowledge (e.g. assumed Roma social norms that do not exist) or racist assumptions (i.e. assumed natural Roma incapacities) when justifying their own standard of not consulting the Roma themselves. In turn, this non-Roma discrimination, racism and dysfunctional support directly contributed to the Roma situation of poverty, segregation and substandard infrastructure (e.g. municipal representatives neglected the maintenance of community infrastructure within the settlement).

The drawbacks in adherence directly supported the Roma self-exclusionary ideology and misinformation by presenting arguments against adherence. For instance, Roma proponents of nonadherence to outside standards would often quote their personal negative experiences with restrictive aspects of adherence as their reasons for nonadherence (e.g. detachment from family during hospitalization).

4.5. Discussion

In our study, we explored local-level mechanisms supporting segregated Roma nonadherence to clinical and public health recommendations. We identified seven such mechanisms: the Roma situation of poverty, segregation and substandard infrastructure; Roma socialization into their situation; the perceived value of Roma alternative practices; exclusionary non-Roma and self-exclusionary Roma ideologies; discrimination, racism and dysfunctional support towards Roma by non-Roma; and drawbacks in adherence. We found that these mechanisms formed an inter-locked system controlled by and operating through both local Roma and non-Roma.

We found Roma nonadherence practices were being directly supported by non-Roma practices of discrimination, racism and dysfunctional support as well as by the Roma situation of long-term multi-dimensional segregation. This matches previous research well. Janevic et al. (2011) distinguished three levels of racism in a study on Roma women's access to prenatal and maternity care in Serbia and Macedonia: internalized racism, personally-mediated racism and institutionalized racism. Most of the processes through which they exemplified these levels are corroborated by our findings and examples, as well. Our findings thus confirm that both the current and historical non-Roma discriminatory approach to Roma still very much negatively affects CEE Roma adherence to clinical and public health recommendations.

We found that discrimination and segregation steadily generated frustrating experiences for Roma youth, which significantly contributed to the formation of adult Roma identities leaning towards deliberate and proud development of practices alternative to adherence. Previous research on the negative effects of discrimination and segregation on health-related practices has typically focused on processes working as direct everyday constraints to healthier behaviours, regarded as such also by members of the negatively affected minorities themselves (cf. Bailey et al. 2017; Janevic et al. 2011). Our findings show how non-Roma discrimination and Roma multi-dimensional segregation might significantly support Roma nonadherence practices not only as direct barriers but also through shaping the identities of Roma with respect to health. This finding also offers an intelligible non-racist explanation for the non-Roma neighbours' common experiences of deliberate non-adherence of segregated Roma, even in the absence of any apparent imposed constraints.

For our Roma informants, racist and racialized ideologies appeared to serve as direct inspirations for the reasoning they used to explain their negative experiences with adherence. In current health-research approaches (cf. Bailey et al. 2017; Janevic et al. 2011) such ideologies, i.e. rendering minority people naturally less capable of adherence, are usually understood as adverse to health inequalities, because they shape existing and have shaped majorities' practices towards minorities. Our findings show how local Roma youth, socialized under the influence of such ideologies, tended gradually to become adults understanding themselves as naturally less competent and more likely to fail at adherence. Social scientific research of racial domination has long recognized similar vicious circles of racialized self-fulfilling prophecies as being behind practices supporting ethnic inequalities (e.g. Fanon 2008; Fassin 2011) and were also recently summarized by Grill (2017) directly for Slovakia. Our findings thus show how along with supporting non-Roma discrimination of Roma, racist and racialized ideologies might also support Roma nonadherence through the process of Roma socialization.

We also found that our informants' nonadherence practices were supported by the perceived drawbacks in adherence. In research on health inequalities as well as in related interventions, clinical and public health recommendations are usually understood and used as standards which most people familiar with their functionality and possessing means for adherence to them consider as appropriate. However, in-depth qualitative research often finds people with good understanding and sufficient means still resisting such standards for a great variety of other reasons – including the view they possess better alternatives (Merrild et al. 2017; Trostle 2004). In their own view, our informants were sometimes capable

of coming up with alternative practices, leading to outcomes of possibly comparable health-effects and more positive social side-effects. This finding supports a view common in other ethnographies of segregated Roma and analogous groups (e.g. Stewart 1997; Tauber 2006; Williams 2003): that these groups sometimes carve out socio-material niches for themselves that enable the development of genuine lifestyle alternatives that cannot be downplayed by outside standards as mere rhetoric or as something only segregated Roma can experience as valuable due to their previous socialization into segregation.

4.5.1 Strengths and limitations

The main strength of our study is its sociologically well-theorized and applied approach. The use of ethnographic methods enabled intimate access to local everyday settings, local people and their practical reasoning. The systematic interviewing across several local stratifications allowed for local representativeness as well as for topical omissions in the previous less-systematic phase to be considered. The follow-up communication enabled additional reflections of preliminary interpretations by local core informants. Choosing structural-constructivist sociological theories and the WHO framework on social determinants of health (WHO 2010a) strengthens both the sociological and public health significance of our results.

Our research design and our reporting also had some limitations. First, the field-work, coding and most of the analyses were performed by a single researcher, limiting the potential for inter-personal corroboration. However, this is standard in ethnographic research, given the logistic difficulties connected with embedded research. Second, the researcher conducting the field work was a male, which may have influenced the reporting by women due to existing local gender power-imbalances. This may have resulted in, e.g., underreporting of gender-sensitive issues. However, we think that this bias is rather limited, as the first author also experienced numerous intimate conversations with local women across generations which included strong criticisms of local male and female roles. Third, it was impossible to remain personally embedded in the settlement during the full study-period. Nevertheless, throughout the research period the first author did stay personally very close to members of one of the three major local extended families which he kept visiting. Fourth, given the author's embeddedness within the Roma settlement, data on local non-Roma views and practices were much more mediated compared to the data on local Roma. However, all assertions implying non-Roma social norms or practices were still

based only on real and documented cases. Despite all the reassuring circumstances just mentioned and the above discussed general good match of our findings with other published research, the presented framework cannot be generalized.

For an additional published discussion regarding this study see Annex 4.4.

4.5.2 Implications

Future research and interventions aiming at behavioural changes of segregated Roma towards adherence to biomedical recommendations should include discussions with the Roma about whether some of their identity-related preferences for nonadherence might not present a case of symbolic violence (Bourdieu 2000), i.e. values historically imposed on their communities by powerful non-Roma. Second, interventions need to address the local anti-Roma prejudices and malpractices of local non-Roma, as well as the influences of more distal actors and processes that support such local mechanisms (e.g. poor education and media coverage in CEE regarding racism and Roma history and conditions). Third, the research and interventions should always carefully examine the health-related outcomes and social side-effects of eventual alternative Roma care practices.

4.5.3 Conclusions

Segregated Roma might be doing less for their health due to interlocked systems of local-level mechanisms, controlled by and operating through both local Roma and non-Roma. Racist non-Roma ideologies, internalized by Roma into a racialized ethnic identity through socialization, and drawbacks in adherence might represent powerful, yet neglected, mechanisms supporting segregated Roma nonadherence.

Annex 4.1 Kinds of reasons the Roma had for nonadherence to clinical and public health recommendations

We identified 13 kinds of reasons. During the analysis, we realized that some of the reasoning was framed and explained by the local Roma informants as structural constraints: “I would like to adhere to this, but I cannot, because here we lack...”, while the remaining reasoning was framed and explained as individual preferences: “I could adhere to this, but I don’t want to, because I prefer...”. In addition, in the second case, the preferences were typically accompanied by spontaneous expressions also in collective-identity terms (“Here, we / Roma prefer...”). Below, we report according to this distinction, as it informs where cooperation of the

targeted Roma in eventual interventions might be anticipated more readily (the perceived structural barriers), where not (the preferences) and why, according to the target population itself. After a brief basic description, by each kind we follow with: an estimate of its variability and validity, i.e. how occurrence of such reasoning varied across local strata and how the declared reasoning differed from actual practice in some cases; public health relevance, i.e. for which exposure domains and elements this kind of pro-nonadherence reasoning was potentially relevant; and illustrative examples.

Kind of reason	Description	Variability and validity	Public health relevance	Examples
Kinds of reasons framed as imposed lack of means				
Lack of knowledge	Clinical or public health recommendations or healthcare services information not known or not practically understood	More common with decreasing social status and in men	All exposure domains	<ul style="list-style-type: none"> Unknown nutritional requirements for newborns, certain diseases and diseases processes, smoke toxicity, etc. Poor practical understanding of recommended medication regimens Poor understanding of hospitalization requirements
Lack of funds and sustenance opportunities	No savings, monthly insolvency regarding most basic needs, no legal employment and long-term income insecurity	Not common only in several highest-ranked households in some periods; more intense with decreasing social status	All exposure domains	<ul style="list-style-type: none"> Highest-ranked households sometimes could not afford transportation costs related to management of chronic diseases Lowest-ranked household members could rarely afford prescribed medicines requiring supplementary payments
Inadequate infrastructure	Missing or dysfunctional basic public infrastructure and household amenities	Somewhat less frequent in several highest-ranked households; more severe with decreasing social status	Material circumstances (incl. environmental exposures), community and personal hygiene	<ul style="list-style-type: none"> Single highest-ranked household possessed a bathroom and laundry machine with majority of households not possessing any water taps All households used provisional dry toilets, wood stoves for both heating and cooking, and many only possessed provisional illegal connections to electricity There was no public lighting, sewerage system and functional waste-disposal scheme in the settlement
Lack of self-esteem	Hesitance regarding social transactions with non-Roma outside the local village due to stigmatization, lack of knowledge and lack of communication skills	Somewhat less frequent only in several highest-ranked households; greater with decreasing social status	Healthcare use; linking and bridging of social capital	<ul style="list-style-type: none"> Even the highest-ranked people often hesitated regarding, chose not to take part in, or opted out of recommended clinical scenarios halfway, quoting “too much” of “too confusing and embarrassing dealing” with healthcare service provider staff, etc.

Kind of reason	Description	Variability and validity	Public health relevance	Examples
Kinds of reasons framed as imposed lack of means				
Lack of communication skills	Communication problems due to own lesser competence in Slovak, esp. in technical terminology and standard communication styles, and general non-Roma incompetence in Romani**	Somewhat less frequent only in several highest-ranked households; more severe with decreasing social status	Healthcare use; linking and bridging of social capital	<ul style="list-style-type: none"> • Even highest-ranked people had difficulties understanding their diagnoses and related clinical recommendations unless carefully explained at a relatively slow pace and translated into lay Slovak • Single local clinical practitioner occasionally attempted use of single Romani words upon trouble with medical interviews (anamneses)
Lack of means to prevent mistreatment by non-Roma	Unavailability of effective procedures to ensure one will not be treated impolitely, harshly or offensively once identified as a Roma	Somewhat less frequent only in several highest-ranked households; greater with decreasing social status	Healthcare use; linking and bridging of social capital	<ul style="list-style-type: none"> • Some people, typically the highest ranked, were better equipped (better clothes, better knowledge and communication skills, lighter skin) for strategic concealment of their Roma origin and for effective negotiation of fairer treatment (e.g. through polite expressions of loyalty) • Most other people felt avoidance of individuals with a racist or discriminatory track-record was the only effective strategy of prevention against own mistreatment within the healthcare services
Lack of trust	Doubting functionality of clinical and public health recommendations and competence or intentions of healthcare practitioners	Only occasional across social levels (typically based on incidental individual negative experiences or on rumours of the same)	All exposure domains	<ul style="list-style-type: none"> • Doubts regarding functionality of dietary recommendations with respect to chronic diseases • Doubts regarding safety of narcotics • Conviction of the incompetence of an allegedly alcohol-dependent paediatrician • Suspicion of bad intentions by overtly anti-Roma practitioners

***While most local Roma understood and spoke Slovak fluently, their mother language was Romani, i.e. a language closest to modern Hindu (Matras 2002)*

Kind of reason	Description	Variability and validity	Public health relevance	Examples
Kinds of reasons framed as personal / Roma lack of motivation				
Moral preferences	Inappropriateness of adherence to recommendations expressed in racialized and gendered ethnic terms; general or relative in comparison to local alternatives	Common in all strata as rhetoric; in practice, not followed as strictly or at all with respect to children and with increasing social status	All exposures	<ul style="list-style-type: none"> • For adult men, attentiveness to one's own health and careful adherence to clinical and public health recommendations was considered "too non-Roma-like" (gadžikano) and "too feminine"; women caring for every-body's health was by everybody considered "naturally" more appropriate "certainly, by Roma" • Highest-ranked adult women kept experimenting with adherence to recommendations (e.g. regarding management of chronic diseases and exercise), but often in concealment due to embarrassment and arguing by dropouts with relief; they were "not that non-Roma-like after all, despite being snobby" (gizdave) • Regarding health problems in children and elderly, especially in acute cases, wherever required means were available most adults tried to ensure adherence to clinical recommendations
Aesthetic and sensory preferences	Inappropriateness of adherence to recommendations expressed in aesthetic or sensory terms; often accompanied by statements of this being an ethnic trait; general or relative in comparison to local alternatives	Equally common across local stratifications	All exposures	<ul style="list-style-type: none"> -Any recommended practices or serious discourses concerning one's bodily functions, especially regarding lower half of the body (e.g. personal hygiene, treatment of health problems, including genitalia or feet and condom use) were regarded as highly "disgusting and embarrassing for Roma" and as such remained contained within the individual's most private sphere and barely practiced (e.g. secrecy and hesitance regarding installation and maintenance of bathrooms and toilets, preventive gynaecological check-ups, sharing of related knowledge) -Other recommendations-related phenomena, similarly avoided as "disgusting", "unattractive" or "unbearable" in contrast to local alternatives, included e.g. most healthy foods, work-related safety measures; silent, solitary living-spaces and places where people have died (e.g. hospitals)

Kind of reason	Description	Variability and validity	Public health relevance	Examples
Kinds of reasons framed as personal / Roma lack of motivation				
Effectivity of local social norms, public control and violence	Conviction that local public rules, surveillance, peer pressure and socially accepted patterns of physical violence (i.e. among partners and towards children) presented sufficient measures to prevent socially unacceptable health-related practices	Equally common across local stratifications	Promiscuity, birth-control, all exposures by children	<ul style="list-style-type: none"> Adherence to the social norm of unacceptability of unmarried girls and women spending any time alone with unrelated adult men was being carefully monitored by the whole public, breaches were strictly sanctioned by ostentatious partner violence, and this practice was considered and praised by both men and women as "appropriate and effective" also privately Strict adherence of children to any procedures considered appropriate by adults – including clinical recommendations – was imposed by adults as a must, sometimes using threats of physical violence or violence, and this practice was considered more reasonable and effective than negotiations of the children's understanding and content
Pride regarding and preferential valuation of local knowledge, talents and settings	Deliberate practices of leisure activities understood as health-endangering in the long-term, yet effective and indispensable for handling of psychosocial pressures faced; often accompanied by statements of their ethnic specificity	Equally common across local stratifications	Risky behaviours	<ul style="list-style-type: none"> People commonly expressed that they considered daily smoking, occasional binge drinking, occasional opulent unhealthy foods and occasional gambling necessary to maintain their "sanity" due to the relative harshness of their condition (compared to non-Roma standards) vis-à-vis "natural Roma susceptibility" to pain, discomfort, stress, sadness, etc.

Kind of reason	Description	Variability and validity	Public health relevance	Examples
Kinds of reasons framed as personal / Roma lack of motivation				
Solidarity with non-Roma	Deliberate minimalization of contacts with non-Roma based on the proposition that non-Roma appropriately experience contact with segregated Roma as difficult	Invoked occasionally, equally frequently across local stratifications	Healthcare use; linking and bridging social capital	<ul style="list-style-type: none"> Upon deciding between different clinical scenarios (e.g. regarding hospitalization) or discussing risks of mistreatment in clinical settings, the Roma also commonly expressed and considered pity for non-Roma staff having to endure "the Roma ways they are not used to, don't understand and cannot stand" (e.g. loud large-groups visits)

Annex 4.2 Experiences contributing to adoption of pro-nonadherence reasoning

1) Adherence failures due to imposed constraints

This kind regarded frustrating experiences of young Roma, especially in their late teens and their twenties, willing and attempting to adhere to selected clinical and public health recommendations but finding themselves unable to do so due to constraints perceived as not controlled by the local community. These constraints included local non-Roma racism, discrimination, dysfunctional support towards the Roma, and the Roma situation of poverty, segregation and substandard infrastructure. E.g. young people initially willing and attempting to investigate their health problems gradually developed a feeling of lack of means to do so due to discrimination and racism after experiencing recurrent refusals of services and mistreatment by healthcare staff directly quoting or implying Roma ethnicity. Young families' indebtedness due to transportation and complimentary medication costs connected with management of chronic diseases and their inability to preserve medical documentation due to lack of personal storage space represent common examples of frustrating experiences with adherence failures, understood as being due to dysfunctional support by non-Roma and to the Roma situation of poverty, segregation and substandard infrastructure.

2) Adherence failures due to personal/Roma incapacities

This kind regarded frustrating experiences of young Roma, especially in their teens and twenties, who were willing and attempting to adhere to selected recommendations but found themselves unable to do so due to perceived personal weaknesses. Typically, such experiences were also interpreted by the Roma as collective traits framed in racialized and gendered ethnic terms. E.g. after several

unsuccessful attempts, persons unable to cease smoking gradually started feeling as not being able to do so due to their personal inherent weaknesses. Simultaneously, such developments became publicly interpreted as examples and empirical proofs of "natural Roma (especially Roma women) susceptibility to smoking" or even to "vices in general".

3) Negative aspects of adherence

This kind regarded experiences of young Roma, especially in their teens and twenties, in their own understanding successfully experimenting with adherence in terms of health gains but finding some aspects of the adherence disappointingly negative. The expressions of disappointment were here often framed in racialized and gendered ethnic terms, and in contrast to local non-adherent practices, were considered as alternatives to the recommended adherence practices. E.g. allegedly clinically effective personal experiments with adherence to clinical recommendations regarding personal management of chronic diseases were often experienced as functional in terms of health benefits. However, they were also experienced as intrinsically connected with too substantial losses in terms of other, more important aspects of quality of life, such as: "unbearable" absences from "normal everyday affairs amid relatives", unbearable abstinences from favourite "pleasures", and feelings of loss of a "natural" Roma identity by becoming "too non-Roma like" (gadžikano).

4) Positive aspects of nonadherence.

This kind regarded Roma experiencing some aspects of their nonadherence (both deliberate and resulting from adherence failures) to specific recommendations and of their situation as significantly positive. Often, such positive experiences were framed in contrast to the respective adherent alternatives, and

racialized and gendered ethnic terms were used. E.g. based on an experiment with both alternatives, one of the local extended families developed and held the view that detox and rehabilitation were not a reasonable therapy for alcohol-dependent persons in the settlement. Along with a comparable therapeutic effect, the "Roma way" alternative – taking care of such persons at home with attempts at controlled drinking – was namely experienced as earning substantial relative advantages for everybody involved (less family detachment, no personal estrangement, more personal care, happier patient, happier family, etc. Roma opinions differed here regarding whether such positives would be experienced as equally valuable for Roma and non-Roma due to supposed differences in their "nature" or "natural needs".

Annex 4.3 Ethnographic vignettes exemplifying the most neglected of the identified local-level mechanisms

Roma socialization for their situation / Roma alternative practices / Roma self-exclusionary ideology and misinformation

D was a local young Roma woman (28) who married a non-local non-Roma truck driver and moved out of the settlement to live with him in a distant city. One day, a rumor spread in the settlement that after several years she is coming to visit her family. People from her extended family were expecting the visit with sincere excitement and curiosity, wondering “what she will look like after all these years” and “how she is doing for herself”. On the day D arrived, she received a warm welcome from both local strangers, standing by in front of their homes, smiling and nodding kindly, as well as from her relatives, awaiting her with special meals prepared for this occasion, etc. Stepping out of her own “fancy car”, D seemed nervous but happily moved. She then spent the whole day visiting the households of her closest relatives, talking, catching up with peoples’ personal life stories. As a close relative of my (AB, first author) host, she also spent several hours in the household where I was staying. In the conversation, the youth in particular were curiously teasing out details about D’s current way of life, asking how her work and household were, what friends did she have, how her marriage was, did she enjoy her personal freedom, etc. D was trying to portray her life as a happy one, although also politely stressing how she missed many aspects of the local life. The locals kept praising her achievement (“Oh, you brave girl, one can see you did really well for yourself!”) and kept asking for ever more details. By the end of the day, D was being sent off with as kind a farewell as she had been welcomed with earlier. However, this time she was not able to hold her emotions and, as she was approaching her car, she burst into tears, and with her polite

constant smile gone. This appeared to cause a general embarrassment, as most bystanders now hastily waved to her and hurried back to their homes.

Later in the evening, my host-mother’s siblings sat together in her house for a regular evening meeting and discussion of the affairs of the passing day. I was struck with what followed: the locals started to talk about D and her life as if it was one big mistake. With local youth quietly and carefully listening to the adults’ interpretations, as always, the adults kept reaching a general agreement that D, in the words of my host, “always tended to take things too far in the non-Roma direction (gadžikano), and now she is paying for it”. In these interpretations, her present life was mostly sad: “Yes, she is working. But only as a helper in the local store, making ridiculous money. And there won’t ever be a better job.” “She spends most of her time alone, trapped in her nice apartment as in a prison, with no kids and her husband gone most of the time.” To my question about the level of personal comfort and freedom she had achieved, i.e. something otherwise considered quite valuable locally, my host’s sister replied: “Ok, so she has a shower now. But is she happy? No. Didn’t you see the state of her when she was leaving?” Such interpretations of stories of segregated Roma switching to outside “non-Roma” standards were common and served locally as powerful, empirical arguments gradually adopted by local youth upon their own struggles with experiments with outside ways.

Drawbacks in adherence / Roma alternative practices / Roma self-exclusionary ideology and misinformation

M was a Roma man (50) suffering from alcohol dependency and an older brother of my (AB, first author) high-ranked host mother. During my first year of living in the settlement, M reached a very difficult phase of his sickness, as he lost the ability to take care of himself – several times a week his wife had to carry him home from the local pub. He was aggressive; he suffered from enuresis and encopresis; he had difficulties walking. At this stage, some of his younger siblings from high-ranked households decided to organize and pay the expenses connected with a rehab stay, and they convinced M’s wife to cooperate “so our brother doesn’t die”. Over the next several months, the family kept spending valuable resources to pay weekly visits to M at a state facility located in a forest 70 km away. Each time we came to see M, both during the visits and in the car after we left, everybody tried hard to keep the mood up by stressing how much better M was: “Oh, you look twice as young as when they brought you here!” (“Did you see how he walks by himself again?”) and constant joking. But there were many moments when everybody went silent, and it was palpable that people were struggling not to start crying instead. On several occasions, M couldn’t hold it, and silently cried with his blue eyes wide open, fixating on his siblings. One day he formulated his silent reproach: “The people are not treating me badly here, no. And I get to talk a lot with this one nice non-Roma in my room. But still, I am all by myself here, you see?” After this visit and a quick passionate discussion in the settlement on the evening of our return, a month before the stay’s planned ending, the siblings agreed resolutely with a sense of relief that they were “going to bring their brother back out of there!” In the week of M’s return, his siblings organized a party to celebrate the reunion. The organizers made sure several bottles of M’s favourite vodka were on the table, kept pouring him and he drank all of it. Over the next

weeks, the family’s hopes and plans were to supervise M’s controlled drinking. In the words of my host: “A couple of beers a day will not turn him back to that state he was in.” But they did, and over the next couple of months, everything returned to the state of affairs prior to the rehab.

This time, however, everybody was firm regarding that rehab was no longer an option. I was surprised and kept asking why, considering the rehab and abstinence obviously helped M to get back into shape physically and relieved his family, especially his wife, from tremendous everyday strain and struggle. A close friend, M’s niece (25), somewhat angrily yet precisely summed up most of the answers I was getting: “Look, M is our uncle whom we love. He has always been very passionate about everything but was the nicest man to us before he got sick. It’s your doctors who say drinking is a disease, right? And now that he is sick we should get rid of him, keep him locked up somewhere and deprive him of everybody he loves and of what he likes to do the most in the whole world!? Roma don’t do this. Only you non-Roma have the hearts to do something like that to your close relatives. You should be ashamed of yourself! [...] Everybody knows most people returning from rehabs will fall back to drinking. And this way, he can at least be taken care after by the people who love him. It’s better for everybody!” This story and rationale well exemplify how, according to local preferences, many available recommended treatment venues for chronic diseases, especially where hospitalization required, were considered connected with too many drawbacks in terms of quality of life compared to local alternative approaches.

Annex 4.4 Additional discussion: What Roma nonadherence is likely and what drives it?

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We thank Broz and Nunes for appreciating our study on the drivers of nonadherence to medical recommendations among Roma in a segregated Roma settlement in Slovakia (Belak et al. 2018; Broz et al. 2019). In our reply, we first devote two sections to answering two general questions of the authors about Roma nonadherence. Next, we respond to their additional remarks and suggestions regarding related assessment tools. We close with a brief summary.

Do segregated Roma value their health less compared to poor non-Roma on average?

The segregated Roma we studied probably do value their health less than poor non-Roma. In two related previous studies (Belak et al. 2017a; Belak et al. 2018), we found that the conviction among Roma that adhering to medical recommendations is not appropriate for Roma, naturally and morally, contributed significantly to their nonadherence. We have already discussed in these papers that similar reasoning has been identified among other Central and East European (CEE) Roma, too.

Our studies show why, in regard to segregated Roma in the region, such findings also make very good sense historically. The identified Roma pro-nonadherence norms were directly inspired by racist views claiming that poorer health and lower socioeconomic position reflect specific natural incapacities of the Roma. These views are still common regarding Roma, whereas they have long become much less common regarding any CEE non-Roma (EUFRA 2018b; Schmidt 2019). However, our findings also show why such ethnically framed norms that support nonadherence still would not mean

that being Roma equates to valuing adherence less. First, the identified pro-nonadherence norm itself did not apply to all Roma equally and did not regard all recommendations. Moreover, various Roma individuals tended to prefer and practice different mixes of adherence and nonadherence, with some persons consistently valuing adherence very much compared to local non-Roma standards.

Secondly, we found that the presence of the ethnically framed pro-nonadherence norm itself depended on several other social mechanisms that were primarily not controlled by the Roma in the settlement – including the above-mentioned prevailing anti-Roma ideologies among non-Roma. This means that such “Roma” pro-nonadherence norms are unlikely to affect numerous CEE Roma who are educated, employed, solvent and do not live in segregated enclaves with substandard infrastructure, surrounded by people and services holding racist anti-Roma views (EUFRA 2018b).

Do segregated Roma prefer non-medical concepts of health more often than poor non-Roma?

The segregated Roma we studied probably do not prefer non-medical concepts of health more often than poor non-Roma. Even the poorest, proudest and most nonadherent Roma would not choose this nonadherence due to favoring some alternative concepts of health or illness. Most Roma always tried to learn and to understand medical diagnoses and recommendations regarding their health problems and rarely expressed doubts about their relevance or effectiveness. Paradoxically, this high level of trust seems to have been supported

by the same Roma adaptations to racist anti-Roma ideologies: most Roma were convinced that the non-Roma were naturally much more gifted for understanding “such complicated stuff”.

We indeed found practices and utterances that could easily be misinterpreted as the Roma favoring some understandings of health and illness that deviate from the medical understandings. Firstly, we found that certain states of unwellness were understood and treated by the studied Roma as resulting from and requiring the intervention of magic (e.g. *z očí*, evil eye). Such phenomena were, nevertheless, viewed by the Roma as folk remedies compatible with medicine, adopted from local non-Roma traditions and practiced alike by the local non-Roma.

Secondly, some of the segregated Roma we studied would initially report fatalist views regarding health. However, most of them would later, after becoming personally closer with the first author, share their experiences of healthcare access barriers and their ethnically framed pro-nonadherence norms as the authentic reasons for nonadherence.

The Roma reported as the motive for their initial hesitance to share their authentic reasons that they expected such reasons to be viewed by a non-Roma as unjustifiable and irrational. This sheds new light on the common discrepancies between self-reported and assessed Roma health status mentioned by Broz and Nunes and also on common findings of traditional Roma fatalism regarding health (e.g. Petek et al. 2006). Such findings may also be partially due to the studies not sufficiently accounting for this kind of Roma social desirability vis-à-vis non-Roma researchers.

Assessing Roma nonadherence practically

Based on the above, we do agree with Broz and Nunes that quantitative assessments of differences in the valuing of medically defined health between various social groups can increase the

understanding of respective health inequalities. However, based on the same, we also believe that acquiring adequate tools for such assessments regarding CEE segregated Roma would require intense initial qualitative exploration and rigorous validation directly in the populations of interest, to account for likely significant discrepancies in semantics and interests between the researchers and those being researched (cf. Singer et al. 2016). To the best of our best knowledge, no such tools are available yet.

We did not identify alternative concepts of health and illness among the Roma studied, despite an initial ethnomedical focus based on the Kleinman’s ‘explanatory models’ approach that Broz and Nunes suggest to consider (see Belak et al. 2017a). Nevertheless, our findings do show that appropriate use of such assessment approaches in the clinic (cf. Kleinman et al. 2006) might indeed facilitate the identification of important social drivers behind an individual patient’s nonadherence, including various structural vulnerabilities (cf. Bourgois et al. 2017).

Summary

Our findings do not confirm traditional Roma preferences, either for nonadherence or for alternative concepts of health. Instead, our findings point to another important pathway, via which Roma health status becomes adversely shaped by prevailing racist anti-Roma ideologies. They underline the need to equip epidemiologists, public health practitioners and clinicians with training and tools to more sensitively and effectively account for adverse structural and culture-bound influences on the health of the populations and individuals they focus on.

Chapter 5

Why don't healthcare frontliners do more for segregated Roma?

Submitted

5.1 Abstract

The poor health status of segregated Roma in Central and Eastern Europe is co-maintained by unequal health care. The mechanisms behind this are unknown. We therefore assessed the practices of health care frontliners regarding segregated Roma, mechanisms supporting substandard practices and the frontliners' resilience to such mechanisms. We interviewed and observed 43 frontliners serving segregated Roma during three months at five different locations in Slovakia. Next, through qualitative content analysis we identified in the data three themes regarding substandard practices, 21 themes regarding supporting mechanisms and one theme regarding resilience. We organized these themes into an explanatory framework, drawing on psychological models of discrimination and intergroup contact. The frontliners' substandard practices regarded mostly substandard communication and care commitment, but also some overt ethnic discrimination. These practices were supported by five mechanisms: the frontliners' negative experiences with "problematic Roma patients"; the frontliners' negative attitudes regarding segregated Roma; adverse organizational aspects; adverse Roma-segregation aspects; and adverse societal level influences. Over their careers, many frontliners first felt obliged and diligent regarding segregated Roma patients, then failing, unequipped and abandoned, and ultimately frustrated and resigned regarding an equal standard of care. Health care frontliners' practices towards segregated Roma are frequently substandard. The psychological processes underlying this substandard care are supported by local and societal level structural circumstances. These circumstances cause many frontliners to become cynical regarding segregated Roma over their careers. Frontliners should be supported with skills and tools for handling racism, culture-bound and structural vulnerabilities as well as related professional expectations.

5.2 Introduction

Both the social and health status of segregated Roma in Central and Eastern Europe (CEE) are extremely poor. CEE Roma rank among the largest ethnically defined populations in the region (EUFRA et al. 2012). In their countries of residence, large proportions of these Roma have always faced and continue to face harsh discrimination and the worst living conditions (Crowe 2007; EUFRA 2018b). Consequently, and further exacerbating this general marginalization, segregated Roma in the region suffer from high burdens of both infectious and non-communicable diseases and have the shortest lifespans (Cook et al. 2013; EUC 2014; EUFRA et al. 2012).

The poor health status of CEE Roma is co-maintained by poorer care and access to care, but little is known about what drives and supports these care inequalities. In general, poorer health care for Roma, both in terms of access to and quality of services, has been shown to be common across the region (Arora et al. 2016; Duval et al. 2016; Földes et al. 2012a; Kühlbrandt et al. 2014). However, differences in socioeconomic and other circumstances related to standard health care access between patients mostly fail to explain all of these care inequalities (e.g. Arora et al. 2016; Kühlbrandt et al. 2014). Increasingly, studies have started to focus on whether discrimination within health care systems against Roma is involved (e.g. Colombini et al. 2011; George et al. 2018; Janevic et al. 2017; Janevic et al. 2011; Rechel et al. 2009). These studies have identified indices of discrimination towards Roma across all organizational levels of the health care systems – institutional, personally-mediated and internalized. To tackle discrimination and other eventual processes that make care unequal as well as substandard care practices, the mechanisms supporting them and how such mechanisms can be resisted needs to be known. However, this has not been adequately studied until now.

Slovakia presents a well-suited setting for the exploring the mechanisms underlying the poorer health care for segregated Roma in the region. With approximately 450,000 Roma residents, the country has one of the largest shares of Roma (8%) in all of Europe (Musinka et al. 2014). As elsewhere in CEE, the majority of the country's Roma (over 50%) reside in segregated enclaves, where the socioeconomic and health status of inhabitants are typically extremely poor (Filadelfiova et al. 2012; HepaMeta 2014; Musinka et al. 2014). Likewise, worse access to and poorer quality of health care, as well as discrimination in the health care facilities, have also been found to be common for segregated Roma in Slovakia (CRR 2017; Jarcuska et al. 2013; Kolarcik et al. 2015), although not universal (Sudzinová 2015). In contrast to other CEE countries with a similar general Roma marginalization, in Slovakia the marginalization

persists under a rather strict anti-discrimination legislature, a well-performing economy and an EU-standard health care setup. In turn, it might be easier here to also identify mechanisms supporting unequal care for the Roma independent of unfavorable structural conditions. Also, previous studies have already comprehensively assessed the local segregated Roma's perspectives on and social mechanisms behind the group's health care use (Belak et al. 2017a; Belak et al. 2018), unlike elsewhere.

Drawing on all of the above and focusing on the inter-personal discrimination level, we assessed in a study based in Slovakia the practices of health care frontliners regarding segregated Roma, the mechanisms supporting substandard practices and the frontliners' resilience to such mechanisms.

5.3 Methods

5.3.1 Theory and design

A qualitative study of the involved actors' practices and perspectives presents a potentially productive initial strategy to explore specific unequal care. Unequal care practices have been shown to greatly vary across both socio-political and situational contexts and to be very prone to reporting biases. Assessment of specific practices might therefore greatly benefit from the focus on real-life situations over longer-term periods and incorporating a qualitative focus on both the supposed victims' and supposed perpetrators' perspectives (Lewis et al. 2015; Mullings 2005; Pettigrew 2016; Quillian 2006; Schnittker et al. 2005).

Drawing on the above theory and following-up on our previous exploratory research on the related perspectives of segregated Roma (Belak et al. 2017a; Belak et al. 2018), we designed an exploratory study focusing on the practices and perspectives of health care frontliners serving such Roma. To ensure the indiscriminate inclusion of whatever the frontliners would themselves find relevant, we employed a classic mini-cycle of grounded-theory approach (Glaser et al. 2017). We started our data acquisition with an opportunistic and open-ended fieldwork phase, continued with preliminary content analysis of the acquired preliminary data and finished with a more structured follow-up fieldwork phase drawing on the preliminary analysis.

5.3.2 Samples

In total, we observed and interviewed 43 health care frontliners across six different health care facilities in five different geographical locations, split between two counties with the highest proportion of segregated Roma communities in Slovakia. The frontliners included hospital nurses and physicians working in gynecology and obstetrics, pediatrics and internal medicine wards (31); emergency rescue (ER) assistants and physicians (10); and a nurse and a physician from a pediatric clinic (2). A summary of the samples and the sampling procedures can be found in Figure 5.1.

5.3.3 Procedure

The study took place between April and September 2013 in four stages: sampling of facilities, job-shadowing and informal interviewing, preliminary analysis, and follow-up structured interviews (see also Figure 5.1). For data collection, we combined the methods most often used by ethnographers in organizational research: job-shadowing with informal interviewing and semi-structured follow-up interviews (Czarniawska 2018; Hammersley et al. 2007; McDonald 2005). The fieldwork was performed by the first author. The third aim – assessment of how the health care frontliners resisted unequal care – was included into the study design after the preliminary analysis phase revealed the existence of such resilience. Within the participating facilities, no managers or frontliners refused to participate. Saturation was reached for all topics brought up by the study.

5.3.4 Measures

In the job-shadowing phase, our observations and interviews addressed the initial two aims of the study: 'Are there any substandard practices regarding segregated Roma in this practice? What are they? What supports them?' This fieldwork phase aimed at obtaining initial data regarding the study's original aims, as little influenced by our own theoretical assumptions as possible. In the follow-up semi-structured interviews, the focus on all the study's aims was applied more explicitly and in-depth, according to an interview template (see Annex 5.1). This fieldwork phase aimed at obtaining more systematic data on all the study's aims, including the preliminary hypotheses.

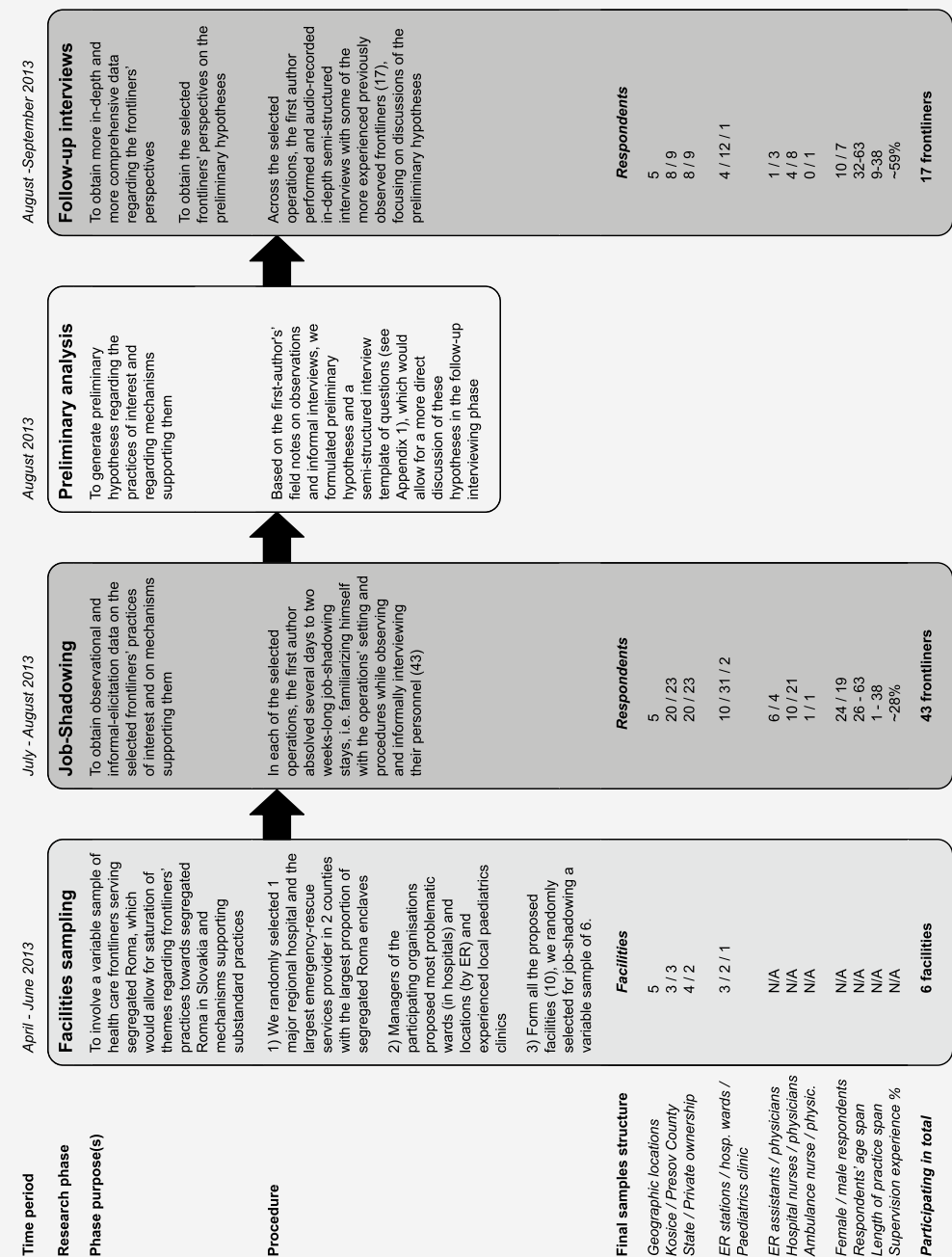


Figure 5.1 Sampling, samples and procedures

5.4.1 Frontliners' substandard practices towards segregated Roma

According to all consulted frontliners, their own and their colleagues' substandard practices towards the Roma mostly concerned substandard communication and substandard care-commitment towards a small proportion of segregated Roma with whom cooperation was very problematic, i.e. not on an ethnic base. However, most frontliners admitted struggling with maintaining standard communication and care-commitment towards all segregated Roma, at least occasionally. This matched our direct observations.

Moreover, several frontliners admitted they knew or heard about colleagues who would also overtly discriminate against Roma patients, especially those supposedly coming from segregated enclaves, i.e. treating such patients worse "because they were (such and such) Roma". Most frontliners declared that they considered such practices as inappropriate and unacceptable, and several suggested they mostly happened in working collectives that included powerful individuals with generally unpleasant personalities.

5.4.2 Mechanisms supporting substandard practices

Frontliners' negative experiences with "problematic Roma patients"

Seven themes emerged that all described distinct and difficult aspects of the frontliners' negative experiences from clinical encounters with some segregated Roma patients: communication difficulties, extreme nonadherence, despised tasks, extreme emotions, safety concerns, lack of respect and conflicts. Patients with whom the frontliners had such experiences were labelled "problematic Roma (patients)". According to all frontliners, these patients only made up a relatively small proportion of all their segregated Roma patients, and the frontliners were assumed to also experience the same kinds of problems with some non-Roma patients (most often quoting examples of people without homes and intoxicated persons). Implying Roma ethnicity in the labelling was nevertheless considered appropriate, because such problematic behavior was supposed to be more common among segregated Roma than among non-Roma. Moreover, some of the negative experiences with "Roma features" were supposed not to occur among non-Roma (e.g. the style and extremity of extreme emotions). These frontliners' impressions of the relative and absolute specificity of "problematic Roma patients" matched our direct observations of patients.

The negative experiences directly supported substandard practices, at least with respect to the "problematic Roma patients" and in situations when they occurred, as they instantly decreased the clinicians' patience and compassion. Moreover, according to some frontliners and our direct observations, such experiences matched and thus further supported some of the frontliners' negative general attitudes regarding segregated Roma and their effects, as discussed below.

Frontliners' negative attitudes regarding segregated Roma

Four themes emerged that all described the distinct negative attitudes that frontliners had towards segregated ("poor", "settlement", "dirtier", etc.) Roma, rendering them as people logistically demanding, weird, immutable and presenting an unfair duty. The frontliners greatly varied regarding how far and for what reasons they considered these characteristics to apply to all segregated Roma. For instance, most considered providing their services to segregated Roma to be an unfair duty for different, even contradictory reasons. Frontliners less prone to negative attitudes towards segregated Roma believed it involved tasks that were appropriate but beyond their job description. Frontliners more prone to negative attitudes emphasized these Roma shouldn't deserve engaged care due to their failing self-care.

According to the consulted frontliners, these negative attitudes also directly supported the frontliners' substandard practices towards segregated Roma patients, as they decreased the frontliners' expectations from such patients and their willingness to treat them with standard levels of compassion and commitment. Next, as acknowledged by several frontliners, such attitudes, i.e. expecting the worse from (such and such) Roma, were likely to increase the frontliners' readiness to experience more and to tolerate less the above-described negative aspects of actual clinical encounters at least with "problematic Roma patients".

Adverse organizational aspects

Three themes emerged that all described distinct adverse aspects of the organizational setups of the frontliners' facilities and operations with respect to segregated Roma: a lack of recognition and commitment from superiors, a lack of serious information regarding segregated Roma and weak competences. Weak competences were spontaneously brought up and emphasized mostly by those frontliners who considered segregated Roma patients to be immutable and highly problematic people. All consulted practitioners considered the remaining aspects important.

These aspects were supposed to support the substandard practices in two ways: via supporting the frontliners' negative experiences with "problematic Roma patients" and via supporting the frontliners' negative

attitudes regarding segregated Roma patients. Both ways were mostly due to the lack of effective procedures, training and tools. For example, most frontliners lacked clear, effective procedures for the prevention and handling of such negative experiences. Moreover, management had high expectations regarding equal care outcomes but did not provide effective related procedures, training and tools. This fed the frontliners' attitudes considering work for segregated Roma to be an unfair duty in this context.

Adverse Roma-segregation aspects

Four themes emerged that all described distinct adverse aspects of Roma segregation: poor hygiene standards, low literacy, fears and related strategies, and substandard infrastructure. Most frontliners acknowledged all these aspects as important, but greatly varied regarding their relative importance.

These aspects were assumed to support substandard practices in two ways: via supporting both the frontliners' negative experiences with "problematic Roma patients" and via the frontliners' negative attitudes regarding segregated Roma patients. The negative experiences were assumed to be mostly due to the decreased capacities of these segregated peoples to maintain general standards. For example, most frontliners understood the generally low literacy standard in segregated settlements as the primary cause of communication difficulties. According to some frontliners and our own observations, the negative attitudes were supported mostly by experiences matching anti-Roma stereotypes. For example, some frontliners interpreted Roma avoidance of services as examples of Roma indifference towards their own health or future in general.

Adverse societal level influences

Three themes emerged that all described distinct adverse societal level influences: poor education and media coverage, lack of vision and commitment, and the under-financing of regional health care. According to most consulted frontliners, these influences supported the substandard practices both via adverse organizational aspects and via Roma segregation. Adverse organizational aspects and Roma segregation aspects were assumed to be supported mostly through the lack of practical vision and related capacities. For example, one consulted manager claimed that no state authorities required monitoring and following-up on likely unequal treatment by Roma outcomes, because if they did "they would make visible something they wouldn't know how to solve". To illustrate the latter pathway: many consulted frontliners claimed that municipal authorities ignored or lacked the capacities to tackle the problem of substandard infrastructure in most segregated Roma enclaves.

According to frontliners with initially no or few negative attitudes towards segregated Roma, societal influences also supported such negative attitudes directly. They noted the lack of appealing narratives that provided alternatives to racist explanations of current segregated Roma specifics, both in public education and media. The importance of this pathway was strongly corroborated by our direct observations, especially in our follow-up discussions of some such alternative narratives with these frontliners. For example, most frontliners expressed interest, gratitude and regrets when we shared our evidence-based interpretation of the mechanisms leading to the present self-exclusionary practices of some segregated Roma (Belak et al. 2018).

5.4.3 Frontliners' resilience to the supporting mechanisms

Beyond the initial focuses of the study, one theme emerged describing how the frontliners resisted the above-presented mechanisms over their careers. In general, they greatly differed regarding which of the above-described mechanisms would apply to them and how. One pattern became clear, however. Frontliners who started their careers with negative attitudes regarding segregated Roma, making up approximately half of those consulted, retained such attitudes throughout their careers – they seemed to have little resilience. Frontliners who started their careers without such attitudes usually adopted them gradually – thus, they were not able to retain their initial resilience.

More specifically, the latter group described their career experience as feeling first obliged and trying, then failing, unequipped and abandoned, ultimately frustrated and resigned from the ambition of equal standard of care. These frontliners described, and we directly observed, many sophisticated strategies they improvised to compensate for specific segregated Roma patients' disadvantages and related extra work, often beyond the frontliners' job duties (e.g. interest-free micro-loans to patients unable to pay varied fees). These frontliners' feelings of being unequipped and abandoned were based in their above-described views on related adverse organizational and societal level influences – they felt that from both their superiors and from the society they were confronted with high expectations yet provided no practical support.

As reasons for their ultimate resignation the frontliners mentioned their experiences that their extra efforts did not make any significant long-term changes for the segregated Roma patients and for their own difficult work situation. In the words of one gynecologist, "sooner or later you will realize you can only choose between useless burnout and

joining your cynical colleagues.” The initial motivation and consequent frustration upon eventual resignation seemed to be rooted ideologically at a personally deep, identity-related level – most such frontliners shared that they experienced taking part in discriminatory double-standard practices as psychologically damaging (e.g. during the interviews, several frontliners cried upon discussing this issue). Also, these frontliners spontaneously stressed that positive personal experiences with a Roma significantly helped them to resist the above-described negative experiences, feelings and attitudes.

Table 5.1 Summaries of identified recurrent themes with examples

For a summary on the theme of the frontliners’ resilience, see the related section in the main text

Theme	Description	Examples
<i>Outcome: Frontliners’ substandard practices towards segregated Roma</i>		
Substandard communication	Use of more directive and less compassionate communication styles towards and about selected patients	<ul style="list-style-type: none"> • General rudeness; frequent micro-aggressions such as: irony (“Dearest madame”), provocation (“Don’t you feel anything for your own children?”), belittling (“I know it’s hard for you to understand”), use of offensive labels behind the back (“our dear Roma co-citizens”, “Gypsies”, “Indians”); strict and loud tone of speech; not answering patients’ questions
Substandard care-commitment	Poorer planning and follow-up on clinical cases of selected patients	<ul style="list-style-type: none"> • Less effort put into planning and supervision of follow-up treatment (e.g. initiation and organizing of surgeries in remote specialist centers or prescribing and following up on complex medication regimens), based on and especially where any indications of the treated patients’ nonadherence occurred to them (e.g. a personal or family history of nonadherence)
Overt discrimination	Avoiding or taking more paternalist, invasive, laxer or offensive approaches to treatment of selected patients explicitly due to their origin	<ul style="list-style-type: none"> • An emergency rescue assistant refusing to help his colleague outside the vehicle in a Roma settlement because he would “not consider Roma settlements to be places any decent people should be required to visit” • Obstetricians preferring caesarean section in the case of segregated Roma women so as “not to have to deal with them personally” • Direct verbal abuse, including racist slurs (e.g. “filthy Gypsy!”)
<i>Supporting mechanism 1: Frontliners’ negative experiences with “problematic Roma patients”</i>		
Communication difficulties	Difficulties understanding what the patients mean and instructing them	<ul style="list-style-type: none"> • Failures in elicitation of “even the most basic information” (e.g. parents’ lack of knowledge on approximate location and basic functions of bodily organs or exact ages of their children) • Inconsistencies in information elicited from patients (e. g. not matching clinical records or patients nodding in agreement to contradictory statements)

Theme	Description	Examples
<i>Supporting mechanism 1: Frontliners' negative experiences with "problematic Roma patients"</i>		
Extreme nonadherence	Pt died because of lasting consequences for patients' health due to apparently deliberate nonadherence to related clinical recommendations	<ul style="list-style-type: none"> • Withdrawals from pre-agreed life-saving surgeries followed by death of the patient • Leaving of children behind alone in the hospitals after birth or emergency treatment • Relatives' failure to maintain basic hygienic status of their children (e.g. parasitosis recurring after being previously cured)
Despised tasks	Tasks experienced as disgusting	<ul style="list-style-type: none"> • Bathing and removal of parasites (mostly lice) from "hygienically neglected" patients • Handling of the patients' "dirty and smelly" clothes, etc. • Examination of patients in poor personal hygienic state • Visits to the "filthy" quarters or households within segregated Roma enclaves
Extreme emotions	Patients or their relatives becoming extremely aggravated and expressive emotionally	<ul style="list-style-type: none"> • Patients' relatives' "loud weeping", "violent arguments", etc. • Self-harm (e.g. hair tearing, banging heads on walls) • Direct personal accusations of clinical failure or racism, verbal abuse, spitting attacks, etc.
Safety concerns	Experiences of feelings of risk to one's own health	<ul style="list-style-type: none"> • Fear of attacks from patients' relatives, where extreme emotions are present (e.g. in the cases of death of patients, especially children)
Lack of respect	Patients' communication styles experienced as impolite by the frontliners (more frequent and more problematic with patients considered well-off segregated Roma)	<ul style="list-style-type: none"> • Fear of contagion during visits to segregated Roma enclaves • Patients not using common polite expressions (e.g. greetings) • Patients not expressing gratitude for help and stressing clinicians' duties (e.g. "It is your duty to help us!") • Patients evoking supposed racism of the frontliners (e.g. "You don't want to help us because we are Gypsies!")
Conflicts	Patients' and their relatives' conflicts with other patients and their relatives and related claims towards frontliners	<ul style="list-style-type: none"> • Both non-Roma and Roma patients' refusals to share hospital rooms with segregated Roma and related conflicts and claims • Loud communication and arguments between segregated Roma and related conflicts and claims from patients ("scenes")

Theme	Description	Examples
<i>Supporting mechanism 2: Frontliners' negative attitudes regarding segregated Roma</i>		
Logistically demanding	Segregated Roma viewed as requiring extreme level of personal assistance upon any service provision	<ul style="list-style-type: none"> • Viewed as typically requiring postponements or remission of fees and supplementary fees • Viewed as typically requiring more extensive and repeated instructions • Viewed as typically requiring extensive personal assistance with navigation through services • Viewed as often missing required documentation (e.g. insurance cards, IDs, referral notes) • Viewed as sometimes requiring language translations
Weird	Segregated Roma viewed as reacting in incomprehensible ways and making irrational decisions	<ul style="list-style-type: none"> • Viewed by some frontliners as often responding with inappropriate emotions (e.g. "They would start shouting like crazy.", "They tend to set up a theater here.") • Viewed as rarely considering long-term consequences (e.g. "They only care about the present.")
Immutable	Segregated Roma viewed as incapable of adopting different kind of practices than they exhibit in the present	<ul style="list-style-type: none"> • Viewed by some frontliners as inert to both standard and tailored activities aimed at their behavioral change (e.g. "The Gypsies will always remain Gypsies, no matter what you do for them!" "It's genetic, you cannot change most of them!")
An unfair duty	Having to work with and for segregated Roma viewed as an unfair obligation in the societal context	<ul style="list-style-type: none"> • Negative experiences from work for segregated Roma experienced as especially upsetting because of the view the Roma should be taking care of themselves ("Why should we take care of their new-borns, when they themselves leave them here behind just like that?!") • Negative experiences from work for segregated Roma experienced as especially upsetting because of the view other actors in the society should be taking care of them ("Is this really my job – to explain the most basic things over and over to them? Aren't they supposed to learn all these things at school? Nobody else is offered such extras here!") • Work for segregated Roma experienced as connected with unrealistic expectations and related personal risks (e.g. superiors asking for communication standards or care outcomes that cannot be achieved; patients, media and activist organizations supposing and seeking the frontliners' professional failures or alleged racism; related threats of personal legal prosecutions)

Theme	Description	Examples
<i>Supporting mechanism 3: Adverse organizational aspects</i>		
Lack of recognition and commitment	Frontliners' superiors and management in facilities do not reflect on the existing frontliners' negative experiences with the work for segregated Roma in practical and effective ways	<ul style="list-style-type: none"> • Lack of interest, guidance and commitment from supervisors when frontliners voice related discontent ("At best, they [hospital superiors] will just nod in understanding and tell you they are sorry, but that there is nothing they can do about it.") • Lack of tools and clear official procedures in place for prevention and management of the care-provision aspects experienced as negative (e.g. guidelines for communication difficulties or regarding recurring demands for segregation of selected patients in hospital rooms) • Lack of compensation for related extra work ("You see, it's [difficult communication] constant extra time that nobody will pay us for. We are being punished financially for serving here.")
Lack of serious information	Frontliners are not being offered and the facilities' standard operating procedures do not reflect on any serious information regarding history, living conditions and perspectives of segregated Roma	<ul style="list-style-type: none"> • Some frontliners expressed interest in non-racist explanations of some of the segregated Roma patients' seemingly irrational behaviors and extreme emotions, of various aspects of their everyday life and living conditions, etc. • Some frontliners expressed dissatisfaction with not being provided practical training specifically regarding segregated Roma or care provision for segregated Roma, which would allow them to deal with related negative experiences less paternalistically yet more effectively
Weak competences	Frontliners feel unable to solve care-related problems or to achieve better care outcomes due to lack of legal authority	<ul style="list-style-type: none"> • Some frontliners claimed diminishing success in achieving segregated Roma patients' adherence to clinical recommendations or facility rules due to decreasing availability of legal disciplining tools ("Before [during the Communist era], the Roma knew they could end up in jail or their kids could be taken away from them, if they didn't cooperate. Nowadays, there are no obligations anymore, only rights!")

Theme	Description	Examples
<i>Supporting mechanism 4: Adverse Roma-segregation aspects</i>		
Poor hygiene standards	Low frequency and thoroughness of personal hygiene practices in the segregated Roma enclaves	<ul style="list-style-type: none"> • Poor personal hygiene state of some segregated Roma patients and their relatives understood by some frontliners as caused by standard lack of effort in the segregated communities ("It's normal not to wash there, apparently.") • High prevalence of hair, skin and gut parasitosis (lice, fleas, helminths) among segregated Roma patients and in their residential enclaves understood by some frontliners as caused by standard lack of effort in the segregated communities
Low literacy	Poor literacy standard in segregated Roma enclaves including health literacy	<ul style="list-style-type: none"> • Patients' and their relatives' lack of knowledge of basic biomedical concepts about the human body understood as part of general illiteracy supposedly normal in the settlements ("People coming from there sometimes cannot sign their names – how could they know anything about physiology?") • Patients' and their relatives' lack of health care services-user knowledge viewed as part of general illiteracy normal in the settlements ("Most people there don't know how to make a polite phone call, what to ask for, etc. And this concerns whomever they need to call, not just to make an appointment.")
Fears and related strategies	Patients and their relatives prevented from effective use of care services due to varied insecurities they share regarding people and processes outside segregated enclaves	<ul style="list-style-type: none"> • Patients' and their relatives' nonadherence and emotions experienced as extreme or weird understood by some frontliners as consequences of fear caused by lack of information and trust regarding people outside segregated enclaves ("Imagine how hard must it be to come here, into such an unfamiliar environment. Perhaps, that's why they act so weird.") • Patients' and their relatives' avoidance of services understood as a consequence of lack of trust towards the non-Roma ("Of course, they don't trust us, the non-Roma, why should they? No wonder they only come here when they absolutely have to.")

Theme	Description	Examples
<i>Supporting mechanism 4: Adverse Roma-segregation aspects</i>		
Substandard	Unavailability of standard household amenities and community	<ul style="list-style-type: none"> Personal hygienic state of some segregated Roma patients and their relatives experienced as poorly understood by some frontliners as caused by lack of infrastructural means
Infrastructure	Infrastructure in most segregated Roma enclaves	<ul style="list-style-type: none"> High prevalence of hair, skin and gut parasitosis (lice, fleas, helminths) among segregated Roma patients and in their residential enclaves understood by some frontliners as caused by lack of infrastructural means Patients' difficulties with maintaining care-related documentation understood by some frontliners as caused by unavailability of safe means for storage in their households
<i>Supporting mechanism 5: Adverse societal-level influences</i>		
Poor education & media coverage	General lack of serious information regarding history, living conditions and perspectives of segregated Roma among the public	<ul style="list-style-type: none"> Some of their colleague's racist views on the Roma understood by some frontliners as consequence of poor media coverage and education regarding segregated Roma ("You [any citizen] keep hearing this [racist views] everywhere: from ordinary people, on TV, from politicians. And not everybody has the willingness or the opportunity to search for something else, a book, to read something serious, e.g. about the history of these 'Gypsies'." "You know what people get taught about the Roma at school, right? [Nothing.]")

Theme	Description	Examples
<i>Supporting mechanism 5: Adverse societal-level influences</i>		
Lack of vision and commitment	General, societal ambivalence regarding goals with respect to and lack of effective activities targeting segregated Roma	<ul style="list-style-type: none"> Many frontliners understood the supposed specificities of segregated Roma they experienced negatively as consequences of varied responsible societal actors' ignorance or incompetence ("The state isn't doing anything about this." "Look at the money NGOs get for Roma all these years. And where are the results? The [segregated] Roma still live in the Middle Ages.") Some frontliners understood the adverse organizational aspects as a consequence of a general, societal lack of vision and commitment regarding segregated Roma status ("But can you really blame our managers [for not being more committed]? Nobody really knows how to solve this problem [Roma segregation and related issues]. Nobody comes up and says: look, this is what works, this is what we need to do, and this is how we do it! I mean, there are loads of populists, but most people realize there are no serious plans.")
Under-financing of regional health care	Lack of financial support to health care facilities outside of centers	<ul style="list-style-type: none"> Some frontliners understood the adverse organizational aspects as due to generally diminishing capacities for regional hospitals ("Look, they are closing these places down to save, without thinking about where will all these Roma women give birth – do you think they pay nurses enough to take sincere care in how difficult Roma patients feel?")

5.5. Discussion

We assessed the practices of health care frontliners regarding segregated Roma, mechanisms supporting substandard practices and the frontliners' resilience to such mechanisms. We found that the frontliners' substandard practices regarded mostly substandard communication and care commitment, but also overt ethnic discrimination. This outcome was supported by five mechanisms: frontliners' negative experiences with "problematic Roma patients", the frontliners' negative attitudes regarding segregated Roma, adverse organizational aspects, adverse Roma-segregation aspects and adverse societal-level influences. Over their careers, frontliners who started without negative attitudes towards segregated Roma patients first felt obliged and industrious, then failing, unequipped and abandoned, and ultimately frustratingly resigned regarding equal standard of care.

We found that the frontliners' substandard practices regarded mostly substandard communication and care commitment, but also overt ethnic discrimination. This matches previous research on discrimination towards the Roma within CEE health care services in two respects: in alike prominent discrimination forms, including the persistence of racist concepts and labelling, and in the discrimination perpetrators' unwillingness to be identified as such (e.g. Andreassen et al. 2017; Colombini et al. 2011; George et al. 2018; Janevic et al. 2017). The finding of frontliners trying to justify their ethnically biased discrimination practices as experience-driven and rational is in line with studies showing the historical mutation of explicit racism within health care settings and beyond into less explicit, more indirect forms (Mistry et al. 2009; Mullings 2005; Sue et al. 2007). Our findings thus strongly corroborate the idea that CEE segregated Roma do face both overt and less direct forms of ethnic discrimination in health care and add that the forms of indirect discrimination are often not understood as racism by their perpetrators.

We found two mutually supportive mechanisms driving the identified substandard practices psychologically: the frontliners' negative experiences with and their negative attitudes regarding segregated Roma. Some previous studies on discrimination against CEE Roma have also identified the negative experiences of health care personnel with and negative stereotypes regarding segregated Roma (e.g. Andreassen et al. 2017; Janevic et al. 2017). Our study adds detailed accounts of how these phenomena might drive substandard practices via negative emotions, and how these mechanisms support each other. These accounts match contemporary socio-psychological models of discrimination and inter-group relations in their emphasis on the crucial role of the perpetrators' negative inter-group emotions and the emotions' close

relations to context-specific inter-group cognitive contents (Kauff et al. 2017; Pettigrew 2016). Our findings thus confirm how negative emotions and stereotypes might form, inter-relate and work behind substandard health care practices towards segregated Roma and exemplify with novel depth how this occurs.

Among the identified negative attitudes, we found that most frontliners considered their work for segregated Roma to be an unfair duty within the societal context. We also found that the rationale for adopting such an attitude varied between frontliners showing more and frontliners showing less resilience to negative attitudes towards segregated Roma in general. These findings resemble the findings of the only other study we found on a similar topic regarding CEE segregated Roma, by Wamsiedel (2018). In Romania hospital triage frontliners also incorporated into their clinical decision-making their personal views regarding both their facilities' capacities and the served minorities' moral eligibility. Our study thus underlines the crucial importance of how health care frontliners understand their competences vis-à-vis varied structural forces, including structural constraints of both their organizations and patients, for the psychology of their involvement in substandard practices.

We found two mechanisms driving the identified substandard practices indirectly at the local structural level: adverse organizational aspects and adverse Roma-segregation aspects. Previous studies have identified the extremely poor living conditions of segregated Roma and health care organizations' failure to accommodate their consequences as important structural drivers behind unequal care provision to this group (e.g. Andreassen et al. 2017; Colombini et al. 2011; George et al. 2018; Janevic et al. 2017). Our findings add a novel dimension to this picture on how and which organizational and segregation aspects negatively affect the psychological capacities of the health care frontliners to treat segregated Roma adequately. Our findings thus support the conclusions of previous studies that improving the care for segregated CEE Roma requires addressing their segregation both outside and through organizational changes within the health care system. This is in line with ecological models that understand ethnic discrimination in health care as practices simultaneously rooted across all levels of society (e.g. Ford et al. 2010a; Phelan et al. 2015).

We found several adverse societal influences to be society-level mechanisms that support the identified substandard practices indirectly. Matching previous related findings (e.g. Andreassen et al. 2017; George et al. 2018; Janevic et al. 2017), the adverse influences we identified included poor public education and lack of commitment with respect to segregated Roma. Extending the previous evidence, our findings show how poor understanding of segregated Roma specifics, especially those

experienced as negative, may mediate several other mechanisms. The poor understanding allowed some frontliners to use the specifics as rational, empirical justifications for their ethnically framed and biased attitudes and practices and prevented others from resisting and opposing such justifications. However, in our follow-up discussions of ethnographically informed non-racist scientific accounts of the specifics (Belak et al. 2018; cf. Stewart 2013) even frontliners initially quoting negative stereotypes showed high interest and appreciation. Our findings thus suggest that intelligibly conveyed contextualized evidence may help to curb ethnic discriminatory practices, in line with recommendations of the classics of anti-racism (Allport 1979; Lévi-Strauss 1952).

Finally, we found that about half of the consulted frontliners showed great resilience towards adopting substandard practices: they began their careers positively, lacking negative attitudes towards segregated Roma, proactively experimented with minimizing negative experiences, cherished positive experiences with Roma and found their own ultimate resignation frustrating. We found no other studies on such processes. However, our findings match two promising propositions in current applied socio-psychological research on discrimination: the already mentioned crucial role of recurrent negative inter-group emotions in the formation and maintenance of negative inter-group attitudes, and the positive effects of positive inter-group emotions by most people (Kauff et al. 2017; Pettigrew 2016). Our findings suggest that a substantial proportion of CEE health care frontliners is ideologically and emotionally prone to resist negative attitudes and discriminatory practices towards Roma throughout their careers but cannot maintain this resistance. Further, our findings show the psychological toll that involvement in a standardized practice of ethnic discrimination might take on the part of at least some of the involved perpetrators.

5.5.1 Strengths and limitations

The main strengths of our study regard our use of ethnographic methods. Our preceding long-term ethnographic research on related Roma practices and perspectives (Belak et al. 2018; Belak et al. 2017b) supported a well-informed sampling strategy. Our careful rapport-building with and open-ended, non-judgmental attitude towards supposed discrimination perpetrators in the initial fieldwork phase enabled personal trust and sincere openness of many of the visited professionals, including regarding their own double-standard practices and related feelings.

The main limitation of our study was that we did not include as consultants segregated Roma patients, i.e. the supposed victim group.

In theory, this could have caused an underestimating of the extent and harshness of eventual frontliners' discrimination practices due to the supposed perpetrators' social-desirability reporting bias. However, given the study's above-discussed critical findings, we believe we were able fully to resolve this issue through inclusion of careful rapport-building, direct observations and critical follow-up phases, all informed by our previous long-term research on the perspectives of local segregated Roma.

5.5.2 Implications

For healthcare practice, in line with the critical-race theory (e.g. Ford et al. 2010b; Griffith et al. 2007) our findings suggest that care professionals need to become supported in skills and tools to better understand and manage racism, culture-bound- and structural vulnerabilities of their patients (Bourgois et al. 2017; Kleinman et al. 2006), as well as related elated expectations. In addition, with respect to Roma use of health-mediation programs for segregated communities (Belak et al. 2017b; OSF 2011) and employment of more Roma clinical professionals should be considered wherever present (Phillips 2011; Thornton 2017).

For future research, our findings suggest that we need applied studies on how CEE healthcare professionals' competence and capacities could be increased with respect to racism (Bailey et al. 2017; Came et al. 2018) and patients' culture-bound and structural vulnerabilities (Bourgois et al. 2017; Kleinman et al. 2006). Our study provides an innovative example of how unjudgmental use of intense qualitative methods may greatly enrich such evidence.

5.5.3 Conclusion

Health care frontliners' practices towards segregated Roma are frequently substandard. We identified an explanatory framework to understand the mechanisms that support substandard practices of health care frontliners towards segregated Roma. Psychological processes underlying this substandard care are supported by local and societal level structural circumstances. These circumstances cause many frontliners to become cynical regarding segregated Roma over their careers. Our framework shows that and why expecting health care frontliners alone to achieve care equity might turn counter-productive. Frontliners should be supported in skills and tools to handle racism, culture-bound and structural vulnerabilities of patients and related expectations.

Annex 5.1 Follow-up in-depth semi-structured interviews template

Leading question(s)	Purpose(s)
Why do you work in this profession?	<i>To enhance personal closeness by sincere interest in motivations (also through related reciprocal comments)</i> <i>To assess the meaning and significance of the job in the context of the respondents' lives</i>
Generally, what do you consider to be the main limitations of your everyday practice on the job, i.e. limitations preventing the work in your operation from being done the way it could and should be done? Why? What and who do you think is responsible for these limitations?	<i>To enhance personal closeness by sincere interest in experienced difficulties</i> <i>To assess the eventual spontaneous (in) significance of Roma-related problems in the context of the respondents' everyday practice</i> <i>To assess the respondents' perspectives regarding mechanisms supporting constraints to their practice</i>
How would you characterize the specifics of Roma patients, if there are any? What proportions of which Roma meet these specifics?	<i>To understand how the respondents defined, identified and classified Roma health problems</i> <i>To assess the respondents' general attitudes regarding (different) Roma</i>
What specifically do you consider to be the main limitations of your everyday practice on the job with respect to Roma patients? To what proportions of which Roma patients does this apply? What and who do you think is responsible for these limitations?	<i>To discuss whatever the respondents considered as problematic in their practice with respect to Roma health</i> <i>To assess the respondents' own perspectives regarding substandard practices and mechanisms supporting them</i> <i>To discuss the respondents' perspectives regarding the preliminary hypotheses on substandard practices and mechanisms supporting them</i>
Are there any substandard practices towards Roma in your practice? What are they? Why do they happen? What could be done to ensure that Roma don't have to face substandard practices?	<i>To assess the respondents' own perspectives regarding substandard practices and mechanisms supporting them</i> <i>To discuss the respondents' perspectives regarding the preliminary hypotheses on substandard practices, mechanisms supporting them and related resilience</i>
Are there any discriminatory or racist practices towards Roma in your practice? What are they? Why do they happen? What could be done to ensure that Roma don't have to face substandard practices?	<i>To assess the respondents' own perspectives regarding substandard practices and mechanisms supporting them</i> <i>To discuss the respondents' perspectives regarding the preliminary hypotheses on substandard practices, mechanisms supporting them and related resilience</i>

Annex 5.2 Illustrative excerpts from semi-structured follow-up interviews

Interview I

Respondent 1 (R1): Emergency rescue physician, female (42), 17 years of practice, private emergency rescue provider, County Presov, Slovakia

Interviewer (I): Main author (AB), Researcher, 35, male, 10 years of practice

[...]

I: And what's specific about them [Roma patients from segregated settlements] in your view? Elaborate a little. When you go to the Roma, do you have an idea that something there will be different...

he has 150/100, and I write it down as arterial hypertension. I give him a shot of magnesium in his bum, so it doesn't have a strong effect, and he gets medicine which doesn't affect that pressure that much, and it doesn't shoot in the opposite direction, and so he doesn't then faint on me, and then I send him out of the ambulance and I don't know what was wrong with him; I don't know whether I've helped him or not and I've done a thing on paper for the insurance company so that I get paid for the trip. And for the lawyers, because the lawyer is unable to assess what happened there, but, really, I am not satisfied in spirit. I really don't know if what I'm doing makes me happy. I don't know if I've helped or not.

R1: Yes, when I go to the white majority, I don't feel that I'll have a problem getting a medical history, medications used, that they will not have the papers at home, that no one will be able to say anything about the patient. This still applies for me in medicine, what old doctors taught me, but maybe some doctors have forgotten this. For me a well-taken medical history, not only on chronic but also acute things, is part of a correct diagnosis, so with 4-5 targeted questions, if I get a coherent answer, I'm simply able to take some direction in these illnesses. I then begin precisely to go through what is troubling the patient;

[...]

I: I take it like this, that we talk about "them" [Roma patients], and in the end I would then somehow differentiate the people in that, of course, this isn't related to all of them, and I know that you don't think this way either. But we talk about these problems, about these specifics, so you come across this there but a lot less among the non-Roma.

R1: Yes. And I'm telling you that when I come across this in a white person [a non-Roma] it makes me a hundred-times angrier than in the Roma, whom I tolerate. Naturally, I don't go into such tailspins, I shout at the white person, I literally shout that he is irresponsible, that he must have the papers at home. And so,

I: I take it like this, that we talk about "them" [Roma patients], and in the end I would then somehow differentiate the people in that, of course, this isn't related to all of them, and I know that you don't think this way either. But we talk about these problems, about these specifics, so you come across this there but a lot less among the non-Roma.

R1: Yes. And I'm telling you that when I come across this in a white person [a non-Roma] it makes me a hundred-times angrier than in the Roma, whom I tolerate. Naturally, I don't go into such tailspins, I shout at the white person, I literally shout that he is irresponsible, that he must have the papers at home. And so,

on paper I with emphasis I again write down his education, the general practitioner, etc.

I: Because you know that this might work...

R1: No, I get angry more because he has the predisposition to say something to me about himself.

[...]

I: When you realize these Roma people are incompetent in regard to their own medical history, then you have the feeling that they are people who actually don't have the opportunity to be otherwise in most cases?

R1: Yes, but another thing is that some of these young people, I have the feeling that they are fucking around with me. This means he is either exaggerating his problem or he doesn't have it and he is only describing it because of something else. What I mean is that these social things around the ambulance I only see according to how the people are gathered [upon arrival of an ambulance], how they treat us, whether there was some stress there before, it's evident in these people whether there was an argument there, often this is so, yes. [...] They want to show that I came to see them, this is more of a social matter. There was an argument and women do this the most; the guys do it, too. This guy wants to show the woman that she made him so angry that an ambulance had to come. And he wants maybe to also show in this way to those that surrounded the woman, that they should support him, take his side.

[...]

R1: And then there are these people [segregated Roma] whom we call "paper collectors". They collect papers from us so, that is the reports that I write. One Roma woman from J., who has an epileptic son, calls for an ambulance daily or every other day or even twice a day because he had an epileptic fit

of the grand mal type. But again, it's difficult to fool me when she tells me that he had a 10-minute long cramp and didn't respond at all and was unconscious. I don't know what to do when she tells me that the fit ended just a moment before and they called us, that fit according to the mother is still going on and that boy that is talking with me is some sort of faker or I don't know, but he is basically without any symptoms after a fit. Simply put, I know what a person looks like after a fit; there are changes and it's always visible on an epileptic. "There is never a good day, I had such a huge fit" ..., bullshit you did. Well, such collectors of our papers and then I ask the rescue workers to look for him, to examine him, do what you want with him, right, and at that moment it ceases to interest me; I'm interested in why I'm there, so I open the doors and say who called for the ambulance and the mother comes and says, "I called the ambulance". [...] She [the patient's mother] collects papers for some invalid pension. And she doesn't know how to do it any other way...

[...]

I: She [the patient's mother] knows she's lying.

R1: She knows that she's lying, and she knows that I know that she's lying. This is the best part about it, and even so she lies to me. And I tell her, dear madam, I've been a doctor for 17 years, you know, it's pretty hard now to fool me. So, you know how you know when your child is lying to you; I see now on you that you're lying to me. "Noooo, I'm not lying!", but now she can't look at me, head down and the work is done, her relatives take her away, they no longer want me to communicate with her. They take her away because they figured out that I've seen through her. This is obvious. They ambush me and now they are in such alert about why am I asking these things, [...] The relatives often begin to attack me: "Treat him after his fit; you're here jumping all over his mother!" I'm not

attacking her, I say, I'm only asking her. He's being treated, don't worry about it; two skilled rescue workers are looking at him; I'm only asking. I want to know why. And they begin to attack me and it's now evident, because I'm going in where they don't want me to go. So, this means that they understand what I want to ask, what I'm thinking about.

[...]

I: And so, what else specific? You said that it's fun there [in the Roma settlements].

R1: It's fun there, then it's less fun when benefits are paid out or when they are drunk or high and families call us to an aggressive and medical treatment isn't really needed; a person only needs to get sober somewhere in a cell for preliminary detention. [...] Why should I take him [a drunken man] to the hospital when is only sloshed and I didn't find any other issues? And even the police pressure me to take him somewhere, and now I'm angry, but not at the patient but at this system, because I have nowhere to put him. He's not ill, so he doesn't belong in the internal medicine department; drunk tanks don't exist anymore; the psychiatric department only takes a drunkard from me only very rarely, so again I'm in a position so stressful and the system forces me to lie. I'll say it plainly. So that I am able to hand the man over somewhere....

I: You have to make up a diagnosis.

R1: Either I argue with the police, which I am very much loathe to do, because in two days I may need them and they'll pay me back in kind, or I have to make up this diagnosis. So [I write down], he fell down; he hit his head or, when purposefully mentioned for this psychiatrist, I would write he was aggressive, threatened to kill or threatened to commit suicide; he can hardly speak, but I write just such bullshit so that the psychiatrist has a reason to admit him and that's it.

I: And what is unique about this, because now and then you go to some non-Roma drunkards, right?

R1: Well, rarely is he [a Roma person] pissed all alone; this is usually a larger group and that's when we are afraid. I don't know whether you've noticed, but only rarely in a Roma settlement does the ambulance driver get out and go to the back.

I: Well, I understood that he is more or less on the alert.

R1: He is on the alert, literally prepared for an attack; he guards this ambulance because the Roma are getting rowdy; it's pointless to explain to them that he came to help [...] Most of this is tied to the period of pay-out of money and...

I: When [social welfare] benefits are paid out?

R1: Yes, it's not permanent there. There are alcoholics, of course, or drug addicts, but that's a different story, nothing exceptional. These are regular Roma who simply drink all at once.

I: And if you were to analyse it a little, that when you come into such a situation, there is there a kind of an emotional charge [...]

R1: Shouting, noise, they [Roma in a settlement] shove us into an ambulance, bang on the ambulance, rock us sometimes with the vehicle. It's really unpleasant, because children step on the running board, once a child climbed onto the roof.

[...]

R1: Drunken Roma don't cause us as much material damage as a drunken Whites [non-Roma].

I: Really?

R1: Yes, certainly. That white person is white, he's a man [confident]. And this Rom is pulled out of the community

and shut up in an ambulance [...] So, he loses the power of the crowd. I'm used to doing this with the most aggressive ones. We have a patient inside the ambulance; we treat him and outside there is this circus. They [the settlement residents] bang on the ambulance, and I don't know what else and I look through the window, I purposefully look at the crowd and they see me. I look at those who are making the most noise, and when your man is close to the ambulance, I open the doors and I pull him inside, grab him by the clothing and say to him, "come, come" and I close the door. And I sit him on the seat which is facing backwards behind the driver and I ask him: "Why are you shouting at us? Why are you banging on the ambulance?" In the meantime, the patient is obviously being treated and this guy is in such a shock, that he is suddenly in some different surroundings and I don't shout at him, I only ask him and he has lost the strength of the crown, so he completely shuts up. It's not yet happened that such a person would run off, that their aggressiveness would endure.

[...]

R1: I am saying they [people in Roma settlements] may be wild, drunk, bang on our ambulance, but they have never purposefully attacked us, "we're going to beat up the rescue workers". Never. And if there was such a conflict, that we had to call the police, and there has been, and now I'm going to shit where I live, it was provoked by us; most of the time the rescue workers lost it, M. lost it, he is a loose cannon; he's really nice, a person with deep faith; he is the station head and has great responsibility and yet, he loses it; it's a character trait.

I: We talked about the fact that he loves order. For him this must be difficult.

R1: This is a character trait. And he simply opens the door and flies at the crowd.

I: He wants to put things in order there?

R1: And he does a hundred times worse; they begin to swear at him, and he swears back, and then it gets thick and then you have to pull M. inside and close the door; they begin to beat on the ambulance because they want to eat him alive, and then I really do call the police, but it hasn't happened often.

[...]

I: And then you said that some of these difficult situations get extremely emotional.

R1: Yes, this is another matter when we resuscitate someone [a segregated Roma person] in a cottage or shack, and it doesn't work. When they [the patient's relatives] see that this resuscitation is failing, that our tasks are pro forma because from me they feel it and now I'm thinking, what do I do, whether I should call the police first and then announce the death to them. They take me to this room, and I run them all outside, but children and adults are glued to the window, and at first, they respect me when I say go out, we need this space, we need to work. But they always leave one person to stand there, perhaps the most responsible, and he doesn't do anything, just watches, but when he sees that this is going in a bad direction he slips away and tells them outside that this isn't going to go well [...] It's better to call in advance, or I seriously consider how to announce the death to them and what to do with the body, because the deceased body is a big problem. They don't want it at home; they don't want to leave it in the house.

I: The people fear the dead.

R1: They are afraid, yes. This is a big problem.

I: As if despite this spectrum of the Roma

that I know, few could endure having a dead body in the house through the night.

R1: This has happened to me three times. It happened in S. There was a community there that just denied the existence of a dead body there. We had to pack it up and take it out. We did it like this: we went to the settlement and called the police, because I have no reason to take a dead body who has officially died at home to the hospital. So, the Roma threatened me with a knife. It was really an unpleasant situation.

[...]

I: Okay, so you are able to communicate well also in such difficult situations [in the Roma settlements]...

R1: It is about communication; all of life is about communication. And not only with the Roma but also among ourselves; when we don't say something then it matters. [...] But it costs me a lot of effort. I'm then a kind of dried prune when I come back to the station. Tired. [...] It's exhausting. To be empathetic is exhausting.

I: It's more demanding than you're used to by non-Roma?

R1: Yes, but no, when you ask whether I work differently with the Roma than Whites [non-Roma]. No, it's the same for me, Roma or White...

I: No, I meant whether this drains you more...

R1: It tires me more than an hour of regular resuscitation where we work hard; I'm more tired after a trip where a small child has a temperature and it's not necessary to take it home; you have to explain to the mother what she should do, and I actually educate her, which her paediatrician or her mother or school or the state or I don't know who should have done long ago, maybe some social worker, who was

there should have taught her how to handle a child with a fever and not me after a 20-minute trip because when I've already begun to resolve it, then I want it to have an effect. May she remember it, understand me, that is repeated explanation, feedback control, I have to ask her, to pull responses out of her, correct her; "no, no"; I write a prescription for the medicine she can give her child and in what dosage: "You can you go to the pharmacy and ask for the medicine for a fever. They'll advise you in the pharmacy." She looks at me, you don't have to ask the name, I say, just tell them how old your child is, how much he weighs and the lady there will advise you. That's what she's there for. They don't know, for example, that they can go to the pharmacy themselves for help, that they can describe some common medical problem and the pharmacist will advise them. They think that she is just a sales person. And this costs me a lot of effort. Because it's hard.

[...]

R1: The boys see this more directly. They look at it as if from above. [...] They see that this is a drunk and gipsy, so it's assumed that he just can't handle his wine, that he's drunk because he wants to be drunk and it's his own fault and that's how they approach it.

I: They follow the hardest stereotypes of the majority. And now in such a team as you have here, are you able to do anything to help the others get rid of their prejudices a little? For their own good as part of their profession.

R1: Well, if some activist didn't come to the Roma, but came to us instead and explained or described this to my colleagues he wouldn't be sniffed at; he could maybe tell of some model situation, maybe if he came with us into the field and observed us there first, let's say, and then came on our trip here. "If you didn't behave like this then that Roma maybe would react like that and your work would be easier because

this wouldn't happen." Such feedback about our behaviour maybe, plus an explanation of their [the segregated Roma people's] mentality that we are confronted with. It's the easiest for a person to judge. It is more difficult to try to be emphatic and to imagine that a person maybe can't or couldn't do otherwise in that moment.

I: This is, in fact, a classic theory, that prejudice is easily transferred because it makes life simpler momentarily.

R1: The prejudice is mainly in that I think that this person wants it this way. That it's their fault.

I: [...] I am sure there are people who might help you in this direction, for example some educated Roma, who know both sides and would come and rouse your colleagues a little.

R1: I can't comment on this generally. I'll not answer this question generally because it depends on character. It's a kind of burnout, some psychologist would have to prepare us in advance for this; certainly not that some educated Roma knocks on our door and sits here opposite to L., who has huge prejudices towards the Roma, and begins to explain something to him. He'd tell him where he could go, and he'd feel good afterwards that he beat your expert, he won't understand that it's for his own good. So, some advance preparation would be necessary. Some activist can't just come in here and talk to us about how brilliant the Roma are...

Interview II

Respondent 2 (R2): Paediatrician, female (60), 31 years of practice, state regional hospital, County Kosice, Slovakia

Interviewer (I): Main author (AB), Researcher, 35, male, 10 years of practice

[...]

I: Regarding the Roma, what would you say is unique about them as patients? What things are found in them more often than with non-Roma? I'm not just thinking of problem things but overall.

I: And the differences between the best and the worst are large?...

R2: There are huge differences, yes this is a different kind of people.

R2: Well, I would say they can be divided. There are those Roma who are really bad and those better and exceptions are enlightened, there are very few of these. The really bad are maybe 20%, and 50% are those who are bad in caring for their child, and then maybe 20% are such who take great care of them, much better, they take care like all white people do, and 10% are those who care better than anyone.

I: Yes, this is my experience, but...

R2: This is totally different.

I: As patients, what else is unique about them for you?

R2: Their children go around very undernourished, neglected, ill, because they live in filth. Their mothers are unbelievably stupid. They don't know how to cook for their child, how to

feed them. They don't know how to sterilize anything; they are very dirty.

I: So, these are the worst, let's say,

R2: These are the worst.

I: And those who are better, what's the difference versus your other patients?

R2: This middle group... There's not a big difference, because their children are better off and their parents care for them a bit better, than those who are just awful. But they also care for their children badly.

I: And those best?

R2: And those best do a great job of caring for them, they take care like everyone else.

I: So, let's talk about this middle group now, please.

R2: This middle group doesn't care for their children well either. They buy soda and sweet drinks and stick them in the mouth of children still in swaddling and give them water [instead of milk or formula] and the children are undernourished, they have diarrhoea, cough and they come to us constantly. And that's the middle group. And then there are those parents that don't have any idea, because they don't have any money. They give their money to usurers and then they don't have change for the bus so they can bring their kids here. These people are terrible. Their kids weigh 4 kg or even less at one year.

[...]

I: And in your daily life, when you do your job, what's the biggest problem for you? What's your biggest stress.

R2: What stresses us the most is that we don't have any social inpatient beds; we don't have the chance to hospitalize these kids. We can have them once

every 31 days, treat them and send them home; only the child goes home and the same merry-go-round starts over and their parents try to pressure us, because they don't have the money for diapers; they have other priorities, like drinking, having fun, and the kids are put aside and then they come to us so that we have them once, the infectious department once, and we turn these patients to the other departments because this child must survive somewhere, and our social workers don't want to put them into children's home. The children's homes are full; I understand that.

I: So, you have the feeling that this is also a problem on the side of capacity, that you should be capable of hospitalizing these people for a longer time or...

R2: For a longer time, we can't, because the health insurance company determined that for 4-5 days when we have these children in our care, that we have to help them, stabilize them and send them home in better health. But their parents don't come back for the children. They don't want them. The children don't wear diapers, although the obligation of every mother when she comes here is to bring the number of diapers we say to bring. We say that when there's a diarrhoea, then we use 10 diapers a day per child. So, we have to take diapers from the storeroom, because the mother doesn't bring any at all; and we ask the parents repeatedly to come for a check-up chest x-ray, etc., we take them home in an ambulance, wait a week, another week, then in some way we get by here. And if the mother doesn't have money, then she's glad her child is here and waits, then she doesn't want to admit that it's her child, so she looks around for a rescue worker or a nurse, for someone to give the baby to.

[...]

I: Social inpatient beds...

- R2: If we had at least 2-3 social beds then we are able to hospitalize such kids. The health insurer wouldn't have to pay, but the Ministry of Health and Social Affairs instead. But they certainly aren't going to give money for this. They're glad it's like this. I was at the social office at two meetings and I asked them that when we write a statement that this child was here and always comes here in terrible shape, why don't they place him in a children's home, resolve it so that we don't have him in that health condition, as it will kill him sooner or later. The social workers said that this child is with us and when we release him, that this is our matter and that they won't place the child elsewhere, because they get rewarded when the child is returned to the family. That's what they tell us, that they just return the child to the family because the mother has a box of children's formula and I don't know what else. Because we've had such children who had inflamed kidneys and the kidneys were infected and in 5-6 years they are waiting for dialysis. So, when such a child is put in a children's home the foster care mother can take care and in maybe 4-5 months to turn him into some kind of person, because otherwise it's just terrible.
- [...]
- I: And are there some specifics in the sense that these Roma patients from the settlement are often "simpler people" that you have to adapt to variously...
- R2: Adapt to what, for example?
- I: I'm asking, for what.
- R2: Why would I? The approach is standard, for everyone the same.
- I: For example, I've chatted with doctors, for instance, this one paediatrician who has worked for 30 years and he said that his practice, his communication with such patients, is systematically more difficult versus standard and that he would appreciate if, in some way, he would be compensated for this.
- R2: I don't have a problem with this. I'm able to communicate with Whites, too; I also speak a little bit of Romani, so I don't have a problem with them. They don't know the language mainly. When you go to talk with them it's as if they don't know what you want, so sometimes they just look at us, but they understand in Romani very well.
- I: This is another thing I wanted to ask about: if the language barrier is a big problem...
- R2: A person has to learn.
- I: But now in this communication...
- R2: A person has to learn, because otherwise you don't find out anything. That's one thing and another is that we have a lot of Hungarian Gypsies.
- I: And you had to learn to orientate yourself, that these are this type of Roma or to guess about the kind of family...
- R2: But the approach doesn't change, whether like this or that. It's always the same. Standard. There is a standard approach to everything.
- I: I understand.
- R2: Whether a white person or different.
- I: Yet, when I spoke with other doctors, they told me that it's hard to maintain these standards when it's not possible, for example, to get a medical history.
- R2: Because they don't know the Gypsy language and if they knew, then they'd find out everything.
- I: And you have the feeling that this should be a part of your work, that...
- R2: It shouldn't be a part of my work, but that's how it is. If a person learns over time and knows what to ask, this isn't an issue.
- I: And do you feel that you should be compensated, because you simply have to do, compared to your colleagues, something extra?
- R2: No, I'm retiring soon. I don't want to do this anymore. My whole life I've done things I didn't want to, but it's okay. A person learns to do it and makes it part of the routine. So, she doesn't have a problem with this.
- [...]
- I: I now want to briefly return to the segregated Roma once again. So, there are bad trends on the part of the hospital and patients overall. But where in your opinion lie the reasons there being this kind of population...
- R2: The Roma?
- I: How is it possible that since the times of Maria Theresa, as you explain, that these standards in half of this population are so low...
- R2: This is more than half with a low standard. It's 80%. They've got this in their genes; they don't need to wash; their children fear water, they bring them here and bathe them a week or two, but they fear water; they don't know it; they're not taught any hygiene. Nothing. They are just natural people, it's the race.
- I: Do you feel that nothing can be done about this...
- R2: What do I know? But this must be taught from a young age. My children were in the bath from the start, but Roma children aren't put in the bath, never; they don't know about it. And to teach hygienic habits from the start is necessary and the adults must have this habit. If parents don't the children don't either.
- I: And for you this is a big problem that the standard is completely elsewhere, so if you could give an opinion what should be done about this. What would come to mind?
- R2: We devote ourselves so much to them and with no result.
- I: And these strategies are different the past few years...
- R2: It's hard to say anything about it, because a person would give everything, and it may not lead to anything. And rumour has it that we kill children here.
- I: Well, this is another matter I wanted ask about: whether you have the feeling that if such [Roma] patients' behaviour towards you has changed in some way.
- R2: Yes, it's much worse.
- I: Worse?
- R2: In the media, they watch television, have a satellite over every shack and in television they see a doctor who does everything badly and that's how they take it then. These people ask for everything possible and if they don't get it immediately, then it's a circus. It's their right, they say, and so on. Just as certain things do typically belong to them, above-standard things don't, and if we offer them something standard and they aren't happy with it, a day or two later a great wave is made, because these are other emotions, another race. It can't be explained, because it's not reasonable. It's hard.
- [...]
- I: Let me ask again about recently the worst and the best experience with such [segregated] Roma, what do you think you wouldn't experience with other patients, or...
- R2: I had one bad experience when we had a child who had pneumonia with a small exudate, we treated him; he was a good child, and we took a check-up x-ray and it wasn't good, so I told the

mother that we'll have to transfer him to a higher workplace, I think this may be a specific process, let's say to T. [...], and the next day the grandmother came here, tore her clothing, lay on the floor, because, according to her, we put the child in an ambulance late. This means they came to T. late and the woman doctor there said that they should have been there by 11 and it's already 1 o'clock. But I don't order ambulances and I'm not going to transfer you by air. So, I don't know. I have [non-Roma] patients who live abroad, come here gladly and they don't have any problems.

[...]

I: Okay, last thing. Different reports about this exist, and doctors have admitted to me that often they lose their nerve, or mainly your younger colleagues that they don't do things completely as they should. I don't know if such things happen or not. What would you say should be done? Who could do what to...?

R2: But there are standards, and these must be observed. There is no problem there and our doctors observe this.

I: Well, that's how it's determined, but it's as if it happens that there are

workplaces where this goes overboard.

R2: No, there aren't. This isn't possible. Not in paediatrics. I don't believe it. I've gone through so many paediatric workplaces and I know who does what. This doesn't happen. No way.

I: I read the worst report regarding a gynaecological-obstetrics clinic; that are workplaces where in fact the clinicians' behaviour is terribly divided and that most of them are like this [poor behaviour towards segregated Roma patients], and when I talked with people who are in charge there, they say it's often the nurses who are like this.

R2: Yes, this is divided, because now they make a section more often by Roma women, because the Roma mothers make such a fuss during birth; it's better to segregate them so that they have peace and the white women give birth happily, I know. But this is discrimination of the Whites, not the Roma. Here in our republic it's now such that Whites are discriminated against; they work for the Gypsies because the gypsies shout about what they want, but OK, that's how we live now.

Interview III

Respondent 3 (R3): Obstetrician, male (41), 17 years of practice, private regional hospital, County Presov, Slovakia

Interviewer (I): Main author (AB), Researcher, 35, male, 10 years of practice

[...]

I: Okay, so now we've come to my primary subject, are you able to say what is specific about the Roma as patients for you...

R3: You mean the community now. There are specifics; we have a relatively large Roma community and it's rising mainly due to numerous births; because when I started here, some 40% of births were Roma and now it's more than 50%, so it's going up with the Roma. In what do I see a problem, I see a small one, not a problem but...

I: So far, no problems, but some details...

R3: Specifics. What is specific to the Roma, as I see it. The Roma are a community that comes from their life, their natural life, and they try to get by in places where I would say certain barriers exist and not just naturalness, so in some things this is positive but here in the hospital it brings a negative side. They are taught to live together in some community or family, and they have big families. We see this here that sometimes they are unable to be alone in rooms, so the community will gather in the rooms. Maybe they are very natural; this is a unique thing, I'd say. Another is the large number of children and maybe also that the Roma live in rather low hygienic standards, that's another. Well, the low level of education, too. I think that it is a specific of the Roma, that they simply don't know how to fall into a regimen for a common examination. When they are scheduled, they just come whenever they want. I don't know what else you're thinking about, give me an example...

[...]

I: Okay, when I say specifics, then it of course is something that doesn't apply to everyone. Do you have a kind of rough idea of, say, a percentage that this specifically relates to? Whether there is some scale because the Roma are varied...

R3: Well, this certainly depends on their background, where the people grew up. Some villages in this region can be very well compared. There are villages where Roma live who are more educated and economically, they are better off and it's visible that the hygienic standard is there, and communication is better. At the same time, I think that within this minority certain communities they also have a different standing towards other communities and it's pretty obvious, these divisions, that often some [Roma] people don't want to share a common room with others. And the less educated community, like in the settlement, they have a big problem in communication and with maintaining hygienic standards and even sticking to the regimen of this department or treatments. The Roma from that lower area, meaning where the hygienic standards are lower, run away pretty often. We don't know how to prevent this, but I would say we don't really actively interfere in this. Because we used to try to do it differently in that we'd call the local police when, for example, when a Roma woman left the maternity clinic for one day and left her child here. The police were called, and they'd bring her back later that day or the next day. This makes no sense, nor do any punishments. It's not resolvable, from my

own experience, I mean. It's hard for me to judge this, why it happens; they say that they want to be home with their family and when it's explained to them that the child needs them more than the family or husband, then they take it differently, that the mother must be with those children, that the husband can't care for them himself. This is one specific of this community with that low hygienic standards and education.

I: And so, these Roma leave their kids here and then return for them.

R3: They return; they know now that we release the mother and child on the 4th day after giving birth. So, they know that on the 4th day they can come and take the kids home. This is one problem. Obviously, another problem with this group where they are less educated is that we admit a patient, a pregnant woman with some complication who must lie here, she lasts 1-2 days, feels better, but it's not resolved because sometimes it's a really serious matter, yet she simply leaves during visiting hours. And the subsequent morbidity is associated with this, sometimes mortality. Simply on this basis that you explain to her and she doesn't understand much. She doesn't know how to adjust.

I: Are specific surgical procedures often linked with this?

R3: Exactly. So, for example, we recently had a woman who had a small child, as if lagging behind in growth as is said, in the 32nd week and the child was 4 weeks smaller and despite the fact that the child had to be monitored, because this can lead to death inside the uterus, it's monitored and she must get some treatment, she on the second day just took off and no one knows where. And now we actually don't know whether this child did not end up dead in the uterus. This was all explained to the patient, but

she simply, I think, didn't know how to evaluate on the basis of this. They are not educated enough, so maybe they don't understand us.

[...]

I: Now, so that I have an idea of the range of this, some estimate. You said that 50-60% of births are Roma and that some of these mothers in some way are complicated cases, that you fear they'll run off.

R3: You mean of those 60%? Well, I think some 10-20% certainly will be.

I: 10-20% of that 60%. So perhaps several times a week.

R3: Certainly. Sometimes three run off in a day. If they are from the same settlement or from the same village and they decide to leave together, and they go. I think we certainly have at least one such case each week.

[...]

I: And if you could illustrate this specific a bit, so what was the worst experience from practice you've had, but with a Roma mother or Roma patient. Then the best.

R3: From the health point of view or...

I: For you personally, what's the worst you've experienced.

R3: What's the worst we experienced? Well, the worse for me was perhaps one situation when a woman with high blood pressure who was pregnant went home, also at her own risk, not even at her own request, she simply left without signing anything, and two days later I was on duty and had to save her as she had a stroke. In fact, she died but the child survived, luckily, and the family adopted it, this was in the 28th week. So that was maybe the worst, in terms of medical care. Well, from these other things, pretty often the Roma come for an examination in a terrible hygienic state. I've experienced that sometimes

this patient came covered with mud, these are still a better state, but the parasites are worse. We see this pretty often. Of course, lice and fleas we see here and there. Once a year, certainly. So, you know, this or something like it.

I: And the best experience? The kind you have the feeling that it's linked to the fact that the patients are Roma, something that wouldn't ever happen with a non-Roma.

R3: Something I would not expect from the Roma, I guess that's what you mean. Obviously, for me the most beautiful experiences is a responsible approach of the patient and I mean in the Roma, because it's a rarity. Coincidentally, we had one such patient recently, who couldn't get pregnant, no, three times she miscarried and was irresponsible, she never came here. But then she managed to get pregnant again and she started to come regularly and even arranged a control examination in P. in the risk clinic, so I saw her as the best that I've seen in recent times. Because there were others before then, but they don't come to mind. This is perhaps the loveliest.

I: And so again, personally what made an impression on you...

R3: Personally, of course, when they say thank you its lovely with the Roma. This is special to them and I appreciate when they meet you on the street and say hello and they know you, and I think that at least a little bit there is a certain respect there. I was pleased by a Roma wedding at the department.

I: A wedding was organized here?

R3: Well the woman was near birth so a wedding at the department was arranged and they got married here and then went to celebrate to our...

I: And you had music here?

R3: Yes, that was a rather happy experience.

[...]

I: And why do you think that some Roma patients are so different?

R3: So, some certainly have genetic dispositions and mainly I think that lies in this community where they live, in my opinion. [...] I think that if they were to grow up in a different community, I'm not 100% certain, but this is my opinion, that if this was just a bit better, this environment, then they would be better off. Because this is where I see the basic problem. I also think a problem is that in the main they don't read much, the Roma, perhaps it's not possible there. This is another thing I think, the lack of education. And I think that there is little contact with the other [better off Roma] community; these [Roma] who are in the limited settlements with the other [Roma] community...

[...]

I: I also wanted to ask whether historically, you see any changes, in these [Roma] patients' behaviour.

R3: Historically. Well, I have to say that I see, historically, because those younger people are so self-confident; but those Roma, at least those from the totally lowest educational groups, are now more self-confident. They certainly have higher claims economically. They dress better and mainly that middle group of those more educated it's evident that they are a little more aggressive. What I mean is that the level of education is greater. I don't know whether I've experienced in these young people that they've signed with an X, but in these older ones I have, and we still do. But no longer in the young.

I: One rescue worker, who worked for 15 years in the Košice Region, told me that he notices that there are some

villages where they are musicians, but not old musician families but simply some people who managed to get settled in Britain. And he follows this phenomenon that those who return, for example, from Britain, are a lot cockier, and that on one hand this is good, because they are more demanding on themselves, then bad because it is pretty hard to communicate with them...

R3: Yes, I'm of this opinion. There are some who, in fact, come back from abroad and so they are more educated and it's evident but there is actually this cockiness is higher in them. And what else seems to me is that these young Roma are completely lacking in work habits and I think this is an issue. These older ones, because, I also go out with rescue workers and I always say that these old Roma come and they're proud, because they worked for 20 years. And to these younger ones, 18-25 years old, who never worked, it doesn't matter at all. I don't know where this comes from, what they live from but at the same time they dress pretty well these young Roma.

[...]
I: And now from a wider point of view, culturally we [non-Roma professionals] do some things systematically otherwise [compared to segregated Roma]? Most of us actually rather modestly say, as you say, that you don't see how this life functions there [in the Roma settlements].

R3: Yes.

I: So, it would be interesting to know more about it in some way.

R3: I think so, yes. I don't avoid this, because I've seen a few films on such a subject and now a relatively large number are made. So, I think that certainly helps, when a person sees this history of development of the ethnicity. A person should take an

interest in this and if there is more available, then I think this is a good thing. I mean a positive thing, too.

[...]

I: And your blood pressure gets up often. Is this psychologically rather demanding with such [problematic Roma patients] for you?

R3: This is demanding, and a person must immediately...

I: You also work a bit slower overall....

R3: A person must steel himself, because if you didn't it would be very bad. You, by doing so, get used to certain things, and then take others a bit more seriously. Because when you ask a Roma woman when she last had menstruation and every third one can't tell you when and you can't even determine when a baby is due, it can be a bit like...

I: You get aggravated...

R3: As in, "since when have you been bleeding?", she'll tell you that not since yesterday but from tomorrow, so that you sometimes you get worked up you work with them, but when you have already worked with them, you take it with reservations. Quite often, you don't get enough information out of such patients, and this sometimes creates a problem with the diagnosis, and then with the treatment there is a problem. They can't tell what they are allergic to, they simply say, "I am allergic to some yellow medications" and you already know, you go to risk afterwards. You give her some medicine, and luckily she's not allergic to it or another medicine from this line and this is quite difficult in this regard, but when a person grows up among them as in this community, where there are a lot of Roma, I think he can take it, so he can deal with the problem better than if someone comes out from the outside.

I: That this requires experience.

R3: Certainly, work with people and experience.

[...]

I: And the last question, some communication tricks, what you've learned...

R3: Certainly. Yes, there are tricks for such [segregated Roma] patients; I think that if you act politely to them this is important, but I think that if you can joke with them a bit, that they like this, too. When they see that you're not having a laugh at them or that you simply communicate with them, then they try to be a bit more open and then they say things in better detail. And, of course, those words, that last menstruation, "when you last had one?", when you ask a Roma woman when she had her last "menstruation", she doesn't know, so these

are the word tricks. And there are psychological tricks, of course; you need to joke a bit when the more aggressive Roma come, not be aggressive yourself, that's for sure. So, behave to them naturally, normally explain things and they then cool a little. But they like a joke, so you laugh a little. And recently one Roma woman in the department tells me that you are so funny, because I told them some jokes. Such a joker. So, you have to know a little bit how to behave with them. Of course, there are different types of people among the Roma, too; some you explain things too in a witty way, though once you insist on your way, you will not get through. You know that in advance. You can talk to most of them in an easy and normal way, with reason and a joke.

Interview IV

Respondent (R4): Paediatrician, female (33), 9 years of practice, private regional hospital, County Presov, Slovakia

Interviewer (I): Main author (AB), Researcher, 35, male, 10 years of practice

[...]

I: Would it be preferable if medical information would all be stored electronically, for example through, e-Health?

R4: In some ways it would, we already have a database like that in the hospital which helps us a lot. For example, when a child is born, we copy the medical history into the central register. So, when the patient comes, we already have all the birth data and don't have to ask the [segregated Roma] mother. When I started working here, I was surprised that a mother had 10 kids and could tell me their weight and size at birth from memory. At first, I was kind of proud of this, wow, but later I found out she just made the numbers up. At first you believe everything they [segregated Roma

parents] say but then you get let down once, twice, three times and it's over. I don't believe them anymore; I don't even ask. I just check the numbers of the new-born myself. They know if it was big or small, if it was born here or in P., we ask them these kinds of things. The general practitioners try, and I think they do good work. They don't send us everything, we try to come to an agreement if the patients need anything [...] The biggest problem is when the [segregated Roma] patients need to go to a bigger city for the examination. They might be fine with P., but might never have been to Bratislava or Košice, they don't know how to get there. They expect an ambulance transfer, but of course the hospital can't give them one because

it's expensive and to the patients it's an extra cost when some patients travel by train. So, I tell them I also travel to Košice, it'll cost them about 5.60€ and then they can just take a bus to the hospital. But some would rather pay 80€ for a car if they can't get an ambulance. I recently learned about this sum, for 80€ is the fee for some usurer who has a car in the settlement...

I: I know that when there's a family meeting or something they prefer to get a private car because they're scared of using public transport.

R4: They are terrified of taking a bus or train. When I tell them to go by train, they are completely frightened.

I: And, for example, no one can ever go anywhere alone.

R4: They think they'll get lost because they don't know it there. But I think they have this feeling that they are viewed as gypsies. I myself see that I've changed. I lived in Košice, in the city, and had some Roma classmates and it wasn't even close to how it is here. Everyone was nasty if one of them came on the bus. They were loud, they stank to me, I would have never sat next to one on the train. That's how I was. When I started working here in K. I started distinguishing among them. There are those that I know are totally fine and those that are still repulsive to me. One time I was going by train and there wasn't anywhere to sit except for one couple with this Roma family. They were totally fine, well dressed, they started eating a snack. I sat next to them and everyone looked at me like I was crazy, but they didn't seem bad to me at all. They seemed better. Yes, I feel like this taught me to separate them, that not everyone in Košice was bad either.

I: But this is something they can't count on very much, when they go somewhere.

R4: I think that when Roma come somewhere and come up to someone and ask directions, then certainly they know that he'll either move away or think they are beggars, so he won't respond. So, they simply don't want to. And for example, this makes me really angry because we invest a lot of care and money, and in the end the result is nothing; we organize for the entire ambulance, for a cardio centre, everything, and [a Roma] mother refuses to enter the ambulance with the child because she's not ready. Because she decided that she's not going.

[...]

I: Several doctors have already told me this, that when they think up some more complex means of treatment, Roma patients often don't adhere to it....

R4: Yes. Although there are more difficult diagnoses and you need some exact treatment rules, some immunosuppressants and so on. For example, they often wrote to us from oncology, that such and such family we do not treat. But it is exactly why. When the rules, deadlines, exact rules of when and how to give, what to do, how to walk, are not exactly followed, it unfortunately doesn't work. It's not that the medicine can't help, but that the patient needs to be isolated somewhere and lie there for half a year until he's healed, but it won't happen. You don't have the capacity for this.

[...]

I: In order to frame it somehow, how much would you guess having the Roma minority patients burdens you in your profession excessively. Do you think you are doing work beyond standard or that there are extra problems because of the fact that you have a large proportion of Roma patients?

R4: I think there is a lot more telephone calls, to all outpatient clinics. The fact that I, for example, am very accommodating towards such [problematic

Roma] patients than several of my colleagues; that when such patients can't call, I schedule an examination for them in advance; I give them medicine, call the pharmacy whether or not they have it, arrange an ambulance, etc. We arrange transport for such a day that we know they'll get money [social welfare benefits], so that they really do come to an examination. On this basis, they are also scheduled in outpatient clinics, i.e. when they have money, on the 16th, 18th or the 22nd. We just adjust the dates for them so that it suits them. You don't have to ask other people [non-Roma patients], you just tell them to go there tomorrow, and you know they'll get on the train and go there. And you don't have to explain it and draw maps for them. Or, for example, what we do beyond standard is exactly how we distribute medicines, because dates need to be followed and some medications should either be ascending or some concentration or gradually increased and now I need to explain what is half a tablet, which is a quarter of a tablet, which is a whole tablet. [...] Recently, one district paediatrician from S. said that she tore a page from her calendar and would stick for each particular day with a tape, whether or not when to take a quarter, a half, when it should be used... And simply, who would talk to you [as a non-Roma patient] like this and what would he explain to you? But when you want things to work as they should, you just have to make some concessions, but of course it costs extra time and nerves. Sometimes we laugh at it, what have we come across this time, but on the other hand, you want to ensure what you ordered is done and when you want to ensure it, so you have to do it so that such patients can understand it.

I: But this is an extra service and if you had to estimate, you said that you have 50% of patients...

R4: At the paediatrics department 72%. I did the statistics last year so at the maternity ward this is 1:1, at the paediatrics 72% Roma for 2012.

I: 72% and so from them how many you'd say are the problematic Roma? An estimate.

R4: Well, maybe a quarter. It's hard to say, because the most problematic families I would say, isn't because of the mother; the most problems are, of course, with the poorest, I suppose, or those you can't agree with and then I'd rather leave those children alone. And those we sometimes keep in the infant department and I know that everything the nurse tells me is true: how it ate, how it crapped, took the medication and I don't know what, there's no problem with this. As soon as the baby's with the mother, the care is no longer there; on the one hand, it helps nurses that the child is happier, it's by its mum, but you no longer have that feedback, all the information you need to treat and monitor. So, I say the worst children, which we already know, are those from the poorest or some of the most underdeveloped families. We preferably keep them alone, and we treat them, and the children actually lie there for a long time in the big department for 3-4 days and only then go home. And sometimes it would need a month or two months to improve some things and we know, that at home it wouldn't happen, so it's preferable to keep the baby for as long as possible.

[...]

I: Well, I wanted to ask if you have the feeling that because of this, that you have such Roma patients, that you are overloaded.

R4: There's enough of us. I would say that this isn't a problem with regard to doctors. But it's worse for nurses, because nurses have to take care for those children, mainly when they have

to constantly deal with those mothers and so on. And as far as nursing care is concerned, there is no problem, because they do their normal work, but in those conditions, there's too little quiet, calmer moments. The mothers are constantly bothering them, smoking, they want to go outside, open the door, visit, bring things in, they'll ring a hundred times. Why is it they can't learn such a thing that ringing and waiting, ringing and ringing, and no matter what you do, it doesn't interest them because they ring, and this is abnormal and it irritates all the nurses. Because us doctors, we have other options, we can go and write a release report on the computer or whatever, but the nurses are always out there in the department. And now we are pretty open with our department's nurses; they can say what they think, and they don't think that much about working in our department, they go to work because they have to work somewhere and they are glad to be here at the hospital. And they say that in the first phase, just coming to the night service they feel like at a station in Bangladesh. I get it. They just live without a bit of peace, they can't sit down and write their papers and go and treat a baby, because they constantly have to deal with the mother. And this one mother has a tooth ache, and the other mother's head aches and I don't know what else, these mothers come up with unbelievable complaints.

I: And there are only a few of them or.

R4: The nurses? It is always as if someone is missing; this job is not easy and also some of them are older, and then they have health issues and then night service...

I: Can't more be hired?

R4: Not really, because the Slovak standards are such that so many patients require so many workers and so there

are problems and of course the money and everything that comes with that.

I: So, for example, if the standards took into account that if, for example, some quota of segregated Roma patients were recognized, another standard...

R4: Maybe it would be, but I doubt that anything will change.

I: Perhaps not.

R4: Probably not. I have no doubt, some extra education, if there were one person here in charge of education or something. For example, I've already looked for some Roma. Some mothers that we've had who were decent, nice, or not yet mothers or just related and were used to taking children from other families and so they lay here, and I saw that they were clever. So, I wanted a sort of brigade to come here, to at least guard the door during visits, to at least open the doors so that it's regulated, so that the nurses wouldn't have to do it. But I just suggested it to them, and they already turned 18 and could work and I helped one write a job application and we agreed that she'll come to tidy up and help, but then she got pregnant, and she already has three children now... And now I know that she's at home, and when I see her now it's as if her head is empty. The message is completely different. She's now a mummy and she's home and that's the end of it.

[...]

I: Now, first more generally, if you could tell in what way are the Roma patients specific for you as patients.

R4: I think I've already said it: what is specific is that they are simpler for the most part and it's necessary to negotiate with them and it's necessary to actually tell to them what legislation stipulates, that you can't effectively inform everyone about every act and about what you do with them, and

what the treatment entails, what are the adverse effects and the contraindications, I say that we do don't devote ourselves so much with this [by these patients]. What we think needs to be done with the child, we simply do it. Of course, we tell the mother, and she usually doesn't understand us, and there is no chance to explain it to her otherwise. When they agree with everything, what I think is, that this still does not cover any legislative dimension at all, whenever something happens. I don't say that for all of them, because some know how to sign very well, but the majority sign with three crosses, so this would never hold up in life. So, these are one or two specifics and there also are the parasites, lice, fleas and similar things.

I: The hygienic standard.

R4: The hygienic standard is something terrible. We can catch here different kinds of things no matter how well we clean the medical rooms, we get bitten and ashamed to go to the swimming pool because I'm bitten and stung from head to toe and only I know that it only relates to my work and nothing else. There are people who are less susceptible, but I am the one who catches every flea that appears in the department, so I still say, God, so far it is said that fleas do not carry anything very serious, but I say maybe I'll be the first on whom something is found. Because I have such fear from this, and the only thing I keep saying is that at least they don't carry and spread HIV. I am glad for this, but once I see it, but they think I don't know how they live in communities, but I think they're so together in that pile. So, praise God...

[..]

I: And those [segregated Roma] parents who come with the kids to spend time here, it is probably also pretty often a misery [their hygienic standard]. And when they have this opportunity, how do they use it or...

R4: They use it, mainly the bathroom. So they bathe then and shower and I don't know what, just then the shower head disappears from the shower and so on, that's it, but I'm not saying they're all thieves, not at all, but rather break it, they don't know how to use it, so that's the problem. But I've heard, for example, in hospital in B, that they deliberately have an above-standard room at the children's ward and that the whole family will come to shower during the visits.

I: So, this would point more to the fact that it's not about the people's habits, but that there is no infrastructure for it where they live...

R4: Where do they live... would they like to bathe like, but well... but there are people, for example, like some children who I feel are afraid of water; it's as if they don't know what bathing is. A child came and the nurse immediately said, did you grow up in a flower pot? But the child's feet were totally black as if they had grown somewhere in a flower pot, so that's how it is in terms of hygiene, but I say, it's always better for children here, because you bathe, wash and cut your hair and then the baby totally looks right to the world. I'm just saying it's not such a problem, it's just a little easier with a child. I think that somewhere in other departments they have a bigger problem with it, with an adult who already has his rights and you can't treat him like that. So, I think we are too accommodating to them, and we treat them nicely, and I have no such feeling that they should feel something bad from us, and now we sometimes say about them that how can a baby be so dirty, how can a new-born baby have really dirty nails and they get offended, and now what can I do with them when they're offended?

[...]

I: As I said, this is not an activist research. But I know that there have been various reports regarding forced

sterilization and these things. Rather, that there is this assumption that if you have it harder, then of course, a person can let herself go, loses her nerves, and so on. For me, rather, this is about trying to find ways to make it easier for all the involved people.

R4: It would make it easier to work if I had two floors, so I would work completely in comfort, so I would separate the small ones from the big ones, they would have more options, there would be the bathroom, there a school, there a gaming room and it would just be different than this all together. Yes, if you want to be together, then let's go to class and let the kids play and there is no problem, but you need to have space for this. And you have to have space to get your work done, to do examinations, etc., anything is possible. Like when there is enough staff, and if both parents and children were actually accommodating ...

I: And you see a chance in the future, that you'll be able here to...

R4: They promised us that they would build an annex, but money was needed for it and we just don't have the money. I always say, and you will not help me with this, but once there was a marketing woman here, and she wanted to find out what was going on in the hospital and what could be improved, and how we should make people to come to our hospital, and I said that if 72% of the people here are Roma, no one else will be looking for us...

Chapter 6

How well do health-mediation programs address the determinants of the poor health status of Roma?

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6.1 Abstract

In Central and Eastern Europe (CEE), health-mediation programs (HMPs) have become central policy instruments targeting health inequities between segregated Roma and general populations. Social determinants of health (SDH) represent the root causes behind health inequities. We therefore evaluated how an HMP based in Slovakia addressed known SDH in its agenda and its everyday implementation. To produce descriptive data on the HMP's agenda and everyday implementation we observed and consulted 70 program participants across organizational levels and 30 program recipients over the long-term. We used a World Health Organization framework on SDH to direct data acquisition and consequent data content analysis, to structure the reporting of results, and to evaluate the program's merits. In its agenda, the HMP did not address most known SDH, except for healthcare access and health-related behaviours. In the HMP's everyday implementation, healthcare access facilitation activities were well received, performed as set out and effective. The opposite was true for most educational activities targeting health-related behaviours. The HMP fieldworkers were proactive and sometimes effective at addressing most other SDH domains beyond the HMP agenda, especially material conditions and psychosocial factors, but also selected local structural aspects. The HMP leaders supported such deliberate engagement only informally, considering the program inappropriate by definition and too unstable institutionally to handle such extensions. Reports indicate that the situation in other CEE HMPs is similar. To increase the HMPs' impact on SDH, their theories and procedures should be adapted according to the programs' more promising actual practice regarding SDH.

6.2 Introduction

In Central and Eastern Europe (CEE), segregated Roma occupy the lowest societal positions according to socioeconomic and health-status measures. Compared with the general populations, they attain the lowest levels of education and income and have the highest rates of unemployment (EUC 2004; FSG 2009). At the same time, they have the shortest life-spans, while facing the greatest burdens of both infectious and non-communicable diseases (Cook et al. 2013; EUC 2014; Hajioff et al. 2000).

Over the last decade, health-mediation programs (HMPs) have increasingly become adopted by CEE state administrations as their main policy instruments targeting health inequalities between segregated Roma and the respective general populations. Modelled on analogous services in Western Europe, most HMPs originally consisted primarily of community health workers facilitating individual healthcare access (Koller 2010; OSF 2011; OSI 2005; WHO 2013b). In countries with the longest health-mediation traditions (Romania, Bulgaria and Slovakia), the initial small-scale projects, predominantly driven by non-governmental organizations (NGOs), have eventually been transformed into more complex, state-backed national-level programs. The countries' officials increasingly present HMPs as central state policies for tackling health inequalities between Roma and non-Roma (EUC 2014; Fésüs et al. 2012; Koller 2010).

Despite their original focus on facilitation of healthcare access, all HMPs also encompass other health-intervention aims and activities. According to contemporary public health theory (Berkman et al. 2014; Krieger 2011; WHO 2010a), many other social determinants of health (SDH) need to be accounted for beyond healthcare access to alleviate existing health inequalities (Figure 6.1). Reviews (JSI 2006; OSF 2011; WHO 2013b) and scarce scientific research (Schneeweis 2013) show that most CEE HMPs also increasingly address SDH other than healthcare access (e.g. knowledge gaps, discrimination, socioeconomic issues).

Scientific studies comprehensively evaluating the theory and practice of HMPs with respect to SDH are lacking. We performed a qualitative evaluation study focused on these aspects of one of the national HMPs, the 'Healthy Communities' program based in Slovakia. The program seemed especially appropriate for such an evaluation, as it ranks among the oldest and largest HMPs in the region and declares an emphasis on health-education rather than on healthcare access facilitation (Slusna 2010). Our study aimed to evaluate how SDH were addressed in the theory and in the everyday implementation of the HMP.

6.3 Materials and Methods

6.3.1 Setting and Sample

During the beginning of the study (May 2014), an NGO owned and ran the evaluated HMP, which at that time covered 144 out of the approximately 800 concentrated Roma enclaves in Slovakia (Musinka et al. 2014). The HMP was undergoing an expansion into new localities, negotiations for more substantial state support, and internal re-assessments of previous criticisms (OSF 2011). The then management of the HMP approached the corresponding author due to his previous ethnographic experience among the program recipients to design and perform a critical qualitative evaluation, which would help identify the program's internal limitations and potentials with respect to positive health effects and to fair power-relations with the targeted Roma communities (we devoted a parallel study to the second aim). In return, the management agreed by written contract to allow the authors independent use of the study data. In the last stage of the study (October 2015), the HMP was co-run by the Ministry of Health and covered 234 segregated localities.

Our final sample consisted of over 70 HMP participants from across the organizational levels and over 30 HMP recipients from the communities served. The organizational structure of the HMP during the study period and the structure of the final sample are summarized in Table 6.1.

HMP organizational structure ¹	Fieldworkers	Coordinators	Central management	Executive board	HMP recipients
	Assistants		Management		
No. of persons	200	20	6	4	Approx. 60,000
Main duties	Community-based health education and facilitation of healthcare access	Support and supervision of the HM assistants	HMP day-to-day management and public relations	Strategic decision-making, fund-raising and lobbying	N/A
Criteria for hiring	Completed elementary education; residency in the community of service & personal motivation (brief questionnaire)	Completed secondary education; proficiency in Romani language; related previous experience and personal motivation (interview)	Previous related experience and personal motivation (interview)	N/A	N/A
Roma / non-Roma Ethnicity	Self-declared Roma, with few exceptions	Self-declared Roma, with one exception	Self-declared non-Roma, with one exception	Self-declared Non-Roma	Self-declared Roma
Approx. female: male ratio	3:1	1:1	2:1	1:1	1:1
Location of participants' practice / target communities	Community-based, 1 per segregated settlement	Rotating visits of 10 assistants working in 1 area	In Bratislava	In Bratislava	Across the country, in 23 counties
Final sample structure					
Number of job-shadowed or long-term observed respondents /	9	1	4	0	18
Study phase(s); Observation length per person	Phase 1; 1-3 weeks	Phase 1; 3 months	Phases 1+2; 3 to 14 days	N/A	Phase 1; 1-4 weeks
Number of occasionally observed and informally elicited respondents	61	6	7	3	39
/ Study phases	Phases 1+2	Phases 1+2	Phases 1+2	Phases 1+2	Phases 1+2
Number of persons who attended both structured and follow-up interviews /	5	4	3	1	0
Study Phase	Phase 2	Phase 2	Phase 2	Phase 2	N/A
Final sample size	116				

Table 6.1 The organizational structure of the evaluated health-mediation program (HMP) and the structure of the final sample

6.3.2 Measures and Procedure

Our evaluation strategy was qualitative: to evaluate the practice of interest we relied primarily on data on the involved actors' knowledge and perspectives as constructed using qualitative research methods (Goodyear et al. 2014). We used the following ethnographic research techniques: long-term personal rapport-building, direct observation, informal in-depth elicitation, field-notes taking, semi-structured interviewing, follow-up interviewing and reading of related documentation (Hammersley et al. 2007; Reeves et al. 2008). As a result, our data consisted of: field-notes on direct observations, on informal elicitations, and on readings of documentation; audio recordings of interviews; and the original HMP program documentation (see Annex 6.1).

The corresponding author performed all the fieldwork in two stages (see Figure 5.1). In Phase 1 (May – November 2014), after reading the HMP documentation, he used the first four ethnographic techniques without any intended focus on the study evaluation aims or theory. This was to discourage schematic accounts of the program and to acquire instead data on the place and significance of the program in the respondents' everyday lives. He job-shadowed several managers and a new group of the HMP fieldworkers in one county (i.e. consulting and observing everybody performing all their main duties), and independently visited the communities the fieldworker group served. In addition, he regularly engaged in occasional observations of other HMP staff and recipients (e.g. at regular regional HMP training sessions and visiting recipient communities). To earn trust, along with everyday reciprocity, he engaged in open discussions with the respondents on their personal aspirations and mutual power relations.

In Phase 2 (December 2014 – October 2015), the corresponding author focused on collecting data according to the World Health Organization Framework for action on SDH (WHO SDH Framework; Figure 5.1) and related literature (Brown et al. 2013; WHO 2010a; WHO 2013a). This was to obtain direct and complete data on how the HMP theory and the everyday implementation addressed SDH. During this phase, the author regularly used unarranged and arranged meetings across the HMP organizational levels and recipient communities (e.g. meetings with the HMP management devoted to other purposes and planned interviews with coordinators) to conduct semi-structured interviews (see Annex 6.2) and later follow-up interviews discussing the preliminary findings and dilemmas regarding the study questions.

We chose the SDH Framework, i.e. a theory external to the program, for evaluation of the HMP's take on SDH for two reasons. First, the SDH Framework presents a well-established and exceptionally comprehensive

expert guideline for tackling health inequalities (Garthwaite et al. 2016; WHO 2013a). It lists, indiscriminately across the traditional bio/psycho/social divides, all that has been shown to affect population health. It includes both local exposures and vulnerabilities – ‘intermediary social determinants’ – as well as more indirect socially driven circumstances affecting the former – ‘structural determinants’ and ‘socio-political context’. Second, reports and research indicate that the range of SDH that the CEE HMPs address is gradually expanding.

6.3.3 Analyses and Reporting

We analyzed the data using directed qualitative content analysis (Hsieh et al. 2005). First, all types of field notes and records of elicitations were transcribed into digital text and merged into a single MAXQDA software database. We then added the HMP original documentation to the database. Subsequently, we coded all texts in the database for relevance to particular categories of the SDH Framework. Simultaneously, we used codes to distinguish between data on the HMP theory and everyday implementation to enable a direct comparison between theory and practice in the analysis and the reporting of results. We coded all text related to how the program was supposed to work as relating to HMP theory, i.e. whether originating in the program documentation or from elicitations. This was because we were interested in the theory both in its normative written form and how it was understood by the program participants. All other text was coded as relating to HMP everyday implementation. Consequently, we created separate summaries covering the HMP theory and everyday implementation through recursive abstraction, i.e. repeated reading and summative abstraction of text coded as relating to the same categories (LeCompte et al. 2013). Upon summarizing, we focused on identification of dominant patterns in the evaluated aspects of the HMP according to the respondents’ and our recorded assertions. We focused simultaneously on capturing eventual differences and conflicts in the recorded assertions between different sources, i.e. various respondent groups, the HMP documentation and our observations.

We also used the SDH Framework as our criterion to evaluate the merits of the HMP regarding SDH. We reviewed and assessed, separately for the HMP theory and the HMP everyday implementation, to what extent were our summaries of the HMP consistent with the SDH Framework’s main assumptions regarding what needs to be addressed to alleviate health inequalities. We report the main identified (in)consistencies below as our main findings, each in juxtaposition with the SDH Framework’s related main assumption.

6.3.4 Ethics approval

The original academic institution overseeing the study (Dept. of General Anthropology, Faculty of Humanities, Charles University in Prague) did not require or issue ethical approvals for qualitative research at the time the field work started. The study was, however, reviewed retrospectively by the current ethical committee of the Czech Association for Social Anthropology which confirmed that the research was carried out in line with the Association’s ethical guidelines which also fits the Helsinki guideline.

6.4 Results

In Table 6.2, we summarise our main findings, i.e. the identified HMP’s (in)consistencies with the SDH Framework’s main assumptions regarding what needs to be addressed to alleviate health inequalities. The findings are presented separately for the HMPs theory and the everyday implementation, with each group of findings further sorted according to the SDH Framework’s original main categories of ‘Intermediary SDH’, ‘Structural SDH’ and ‘Socio-political context’ (see Figure 5.1 and the original WHO source for definitions (WHO 2010a)).

Below, in each paragraph we first repeat each of the main findings from Table 6.2 (italicized) and then we explain it. We specify in the explanations on whose perspectives the finding has been based. In general, regarding the evaluated aspects we found no significant differences or conflicts in assertions depending on the source. Where particular findings were supported by only some types of sources, the other types of sources provided no inputs on that issue or were not relevant by definition (e.g. normative documentation with respect to everyday implementation).

The symbol ☐ designates 'partially', ☒ designates 'yes', and ☐ designates 'no'; we use the symbols to summarize how well the HMP addressed each main category of SDH according to the listed main findings; 2 in the original WHO source [13], "social cohesion" is defined through varied notions of social capital which regard both the intermediary and the structural level.

SDH to be addressed according to the WHO SDH Framework	How did the HMP address the recommended SDH?	
	In its theory	In its everyday implementation
Intermediary determinants: material circumstances; psychosocial factors; social cohesion / capital*; health behaviours; biological factors; healthcare access	Most intermediary SDH were not to be addressed, except for health-related behaviours and healthcare access The program's declared secondary goal, i.e. to facilitate healthcare access, was operationalized more precisely than and in a way logically contradicting the program's declared primary goal, i.e. to educate regarding health-related behaviours	Of all the intermediary SDH, the HMP assistants were most active and successful regarding facilitation of healthcare access The HMP's healthcare access facilitation supported rather than challenged the existing healthcare access-related and other health-related behaviours of some recipients Educational activities aiming at behavioural change were considered inappropriate by both HMP recipients and assistants and neglected or appropriated by the latter, except regarding child and maternal health After earning the HMP recipients' trust, many assistants were successful at inspiring changes in health-related behaviours and helping individuals to cope with their psychosocial struggles Most coordinators engaged in and some were successful at addressing the material-circumstances related issues at the community level
Structural determinants: social position according to education, occupation, income, gender, race/ethnicity; social cohesion / capital?	<input type="checkbox"/> Social positions of the program recipients were not to be addressed systematically <input checked="" type="checkbox"/>	<input checked="" type="checkbox"/> Most coordinators engaged in and some were successful at addressing local issues related to income, occupation and education Some fieldworkers were active and successful at increasing a particular community's social cohesion via increasing their bridging and linking social capital <input type="checkbox"/>
Socio-political context: governance; policies; cultural and societal norms and values	<input checked="" type="checkbox"/> Socio-political context was not to be addressed	There were no systematic feedback or advocacy activities directed outside the HMP beyond activities aimed at strengthening the HMP itself The central management considered the HMP inadequate and too unstable to handle extensions with respect to socio-political context <input checked="" type="checkbox"/>

Table 6.2 The health-mediation program's (HMP) (in)consistencies with the World Health Organization's Framework for action on social determinants of health (WHO SDH Framework)

6.4.1 The HMP Agenda

Intermediary SDH

Most intermediary SDH were not to be addressed, except for health-related behaviours and healthcare access. In the program documentation, no goals, targets or procedures focused on material circumstances, psychosocial factors or social cohesion. Both in the HMP staff's accounts and in related documentation, the HMP primary goal was "to increase the targeted individuals' health-related knowledge, motivation and active engagement" through sustained ad hoc face-to-face "health education" and occasional public educational events. Where requested by either the HMP recipients or healthcare providers, the assistants were also supposed to personally "support access of the communities to healthcare services" via personal facilitation of access for individuals.

The program's declared secondary goal, i.e. to facilitate healthcare access, was operationalized more precisely than and in a way logically contradicting the program's declared primary goal, i.e. to educate regarding health-related behaviours. Even though declaring it a secondary goal, the documentation and the participants described related targets and procedures more extensively and in more detail than the health education. Simultaneously, according to both sources, access-facilitation was supposed to be realized as an unconditioned continuous extra service. As admitted by the HMP staff across organizational levels during the follow-up discussions, the access-facilitation was thus logically set out to support rather than to challenge the recipients' existing health-related behaviours.

Structural SDH

Social positions of the program recipients were not to be addressed systematically. In the later stages of the research, "capacity building" through "an increase in education and employment" emerged as an additional goal both in the documentation and in the managers' utterances. The management described and put this goal forward as related to the structural SDH. However, as acknowledged by the managers in the follow-up interviews, this was "an exaggeration". The capacity building was namely planned exclusively via continuation of employment and work-related training of the individual assistants and expansion of the HMP to new localities.

Socio-political context

Socio-political context was not to be addressed. Neither in the HMP documentation nor in anybody's understanding was the HMP to advocate or to provide any systematic feedback regarding governance, policies or any societal and cultural norms and values ultimately affecting the segregated Roma communities.

6.4.2 The HMP Everyday Implementation

Intermediary SDH

Of all the intermediary SDH, the HMP assistants were most active and successful regarding facilitation of healthcare access. According to HMP staff across organizational levels, the fieldworkers were increasingly approached by the residents of the communities and the local healthcare providers for assistance with access. This was also apparent in new localities, where assistants typically faced an initial phase of distrust from both groups (e.g. they hesitated to accept any offered help, explicitly questioned the assistants' possible hidden agendas). The assistants were active mainly with consultations regarding clinical processes (e.g. interpretation of documentation, home medication planning), facilitation of communication (e.g. accompanying to appointments, translation between Romani and Slovak) and first aid. In addition, they provided on demand logistic help to local public health authorities (e.g. facilitation of water source decontamination or of interventions in outbreaks of local epidemics).

The HMP's healthcare access facilitation supported rather than challenged the existing healthcare access-related and other health-related behaviours of some recipients. All respondents typically found the assistance with access unproblematic and helpful. According to some consulted fieldworkers, however, some of the community residents started to regard this HMP service as their "patient right paid for by the government". For example, the corresponding author witnessed several cases of community residents asking the assistants "to do their duty and bring them their medicine". The management considered this phenomenon "a growing problem that will need to be addressed" and informally instructed the fieldworkers to curb such understanding ad hoc.

Educational activities aiming at behavioural change were considered inappropriate by both HMP recipients and assistants and neglected or appropriated by the latter, except regarding child and maternal health. According to the participants and recipients consulted, unsolicited

face-to-face educational activities and nudging were especially viewed as "disrespectful". Most of the long-term observed assistants admitted that, consequently, they neglected or appropriated this "embarrassing, typically non-Roma-like (gadžikano) part of the job"; e.g. they would over-report the numbers of their edification visits or only visit their own extended family households. The inappropriateness of "edification" was supposed to be due to its patronizing nature ("A proper grown up Romňi will never listen to another Romňi preaching!") and its sometimes-unrealistic content. In contrast, everybody considered occasional public educational events to be interesting and "sometimes also helpful". The managers seemed vaguely aware of such assistants' appropriations but mostly considered them as temporary breaches which tend to disappear as the assistants earn more trust of the recipient community's residents. Also, some managers confessed that the HMP leaders merely copied most of their "health edification" approach from a Slovak Public Health Agency HMP pilot (running in approximately 30 localities in 2008-2011) and declared it the HMP's priority for rather tactical reasons – to avoid conflicts with clinical healthcare professionals "touchy about the program fieldworkers becoming understood as clinicians".

After earning the HMP recipients' trust, many assistants were successful at inspiring changes in health-related behaviours and helping individuals to cope with their psychosocial struggles. According to everybody consulted, after an initial period of mistrust most assistants typically started to acquire new personal relationships with other locals beyond their previous affiliations. For some of these new "friends", the assistants were supposed to increasingly present "surprisingly strong inspiration" or "personal role models" as well as "personal counsellors" regarding psychosocial issues. In the corresponding author's personal experience, the HMP recipients often referred to the assistants as to "our nurses", "despite being poor Roma like us", and shared examples of how the assistants, in the words of one resident, "have taught them to take care of their health properly"; e.g. local women would start better complying with medical recommendations regarding preventative check-ups, infant diet, vaccination plans. The managers were aware of the growing psychosocial counselling demand and claimed to be "currently looking into how to better equip the assistants for it".

Most coordinators engaged in and some were successful at addressing the material-circumstances related issues at the community level. According to all respondent groups, beyond their duties most coordinators thus also seemed to deal with: sewerage, water sources, public lighting, waste disposal, rodent control and disinfection. The management seemed to encourage such deliberate engagements of coordinators informally, mostly through ad hoc consultations. Given the

lack of systematic support, their primary workload and the procedural complexity of most of the issues (e.g. requiring knowledge of related laws and varying negotiation styles), the success in such activities seemed to depend mostly on the personal knowledge, experience, wit and endurance of the individual coordinators.

Structural SDH

Most coordinators engaged in and some were successful at addressing local issues related to income, occupation and education. According to everybody consulted, such issues were typically raised by the assistants upon following individual clinical cases. With informal ad hoc support from the management and depending on individual capacities, the coordinators appeared sometimes to be successful at resolving e.g. indebtedness, loss of employment or unsuccessful admissions to regular elementary schools. Such resolutions were supposed to have a community level impact through encouraging and instructing other locals.

Some fieldworkers were active and successful at increasing a particular community's social cohesion via increasing their bridging and linking social capital. Both in direct relation to their duties and beyond, some coordinators and assistants appeared systematically to work on building and sustaining informal networks of personal long-term cooperation with sympathetic representatives of varied institutions and nearby non-Roma residents. The management informally supported these activities and generally viewed them as, in the words of one HMP executive board member, "an unprecedentedly effective way of connecting the settlements with public resources independently of the often indifferent and sometimes also corrupt and outright racist local municipal authorities".

Socio-political context

There were no systematic feedback or advocacy activities directed outside the HMP beyond activities aimed at strengthening the HMP itself. According to those directly involved and to the author's personal observations, the central management actively lobbied the central state institutions both directly and through the use of mass media. These were, however, exclusively ad hoc efforts aimed at securing and increasing the institutions' support of and involvement in the project itself (e.g. continuation of financial support provided by the Ministry of Health).

The central management considered the HMP inadequate and too unstable to handle extensions with respect to the socio-political context. All respondent groups acknowledged that they kept accumulating extensive experience and evidence regarding structural obstacles the HMP

recipients faced, also at the societal level. For example, they regularly witnessed incidents of neglect and racism by healthcare providers or practical inappropriateness of legislative regulations. The managers did not contemplate any systematic use of this know-how for two reasons. First, they viewed issues related to the socio-political context as lying outside the HMP mandate by definition – since "it is only supposed to deal with health issues". Second, they viewed the program as operating in a generally hostile institutional environment and feared any substantial extensions might undermine the unstable support of external and internal stakeholders. They feared field-workforce overload, escalation of competence conflicts and possible performance decline. In the words of an executive board member, most cooperating entities viewed the HMP as "already a luxury" and the program leaders were thus "better not taking the risk of becoming identified as [human rights] activists [...] at least until the project earns more political leverage through its undeniable achievements".

6.5 Discussion

We evaluated how SDH were addressed in the theory and in the everyday implementation of the 'Healthy communities' HMP in Slovakia. We found that in its theory, i.e. both in its written form and how it was understood by participants, the HMP did not account for material circumstances, psychosocial factors, social cohesion, structural determinants of health and the socio-political context. The program's declared secondary goal, i.e. to facilitate healthcare access, was set out more precisely than and in a way logically contradicting the program's declared primary goal, i.e. to educate regarding health-related behaviours. In the HMP everyday implementation, healthcare access facilitation activities appeared to be effective, well received by the HMP recipients and assistants, and performed as set out by the latter. The opposite was true for most educational activities targeting health-related behaviours. The HMP fieldworkers seemed very proactive and sometimes effective at addressing other SDH domains beyond the HMP theory: inducing desired behavioural changes as role models; resolving issues related to material circumstances, psychosocial factors and social position; and accumulating knowledge regarding systematic local impacts of the socio-political context. The HMP leaders supported such deliberate engagement only informally, considering the program inadequate and too unstable to handle any conceptual extensions.

We found that with respect to known SDH the focus set out in the HMP's theory was rather narrow (see Table 6.2). Similarly, an Open Society Institute (OSI) report reviewing all the HMPs in the region identified all the following SDH among "what current Roma HMPs do not address": income poverty, discrimination, health policy and legislation, and lack of resource commitment and political will (OSI 2005). The latest WHO report on the national HMP in Romania acknowledged the same (WHO 2013b). Despite presenting the most consistent (and often the only) national policies implemented to alleviate the steepest health disparities in the CEE region, in their theories the HMPs thus seem to be similarly constrained to only a narrow section of the intermediary SDH.

We found that in the HMP theory, healthcare access facilitation activities were logically set out to support rather than to challenge the program recipients' existing healthcare access-related and other health-related behaviours. This corresponded with our finding that in the HMP's everyday implementation, many recipients understood and used the healthcare facilitation services as continuous extra free healthcare service. The OSI (OSI 2005) report found similar trends in all of the CEE HMPs: "paradoxically, mediation may serve to increase the distance between patient and doctor, and, unless the mediator seeks to educate the patient, may perpetuate the need for health mediators." A follow-up report (OSF 2011) adds: "[Mediators report that] physicians sometimes asked them to explain things to the patient, rather than the doctor trying to do so. There were isolated reports of Roma health mediators going to social service or doctor appointments without the client." In their current setups and implementation, the CEE HMPs thus seem to hinder their own eventual health-promotion activities (certainly regarding healthcare use) by fostering dependence of the recipient communities on their services, i.e. supporting the medicalisation of communities (Conrad 2007).

We found poor acceptability and extensive appropriation of face-to-face educational activities and nudging targeting health-behaviours within the HMP. So far, very little attention has been paid directly to the educational activities within CEE HMPs elsewhere. Our finding, however, fits well with Schneeweis's (Schneeweis 2013) unique and delicate account of how mediators themselves understand and manage their everyday health-mediation work in Romania. Based on our discussions with the managers, we identified two sets of circumstances possibly contributing to these phenomena. First, there seemed to be little to no methodological consultation involved on the part of the HMP planners with contemporary expertise in health promotion favouring participatory tailoring (Kreuter et al. 2003; McQueen et al. 2007). The conceptual framing and historical links we identified with respect to the formal priority of "health edification" within the HMP suggest it presents only

a residue of the now nearly dismantled Communist public health system (Kringos et al. 2013) and its paternalist approach to Roma (Belak 2015b; ÚPZP 1959). Second, the ethnic framing of the poor acceptability put forward by the involved Roma points to the possibility, long discussed among anthropologists (Stewart 2013), of segregated Roma and analogous groups also constructing their ethnicity in direct opposition to local non-Roma norms. Analogous tensions and practices of appropriation in developmental programs targeting Roma in Romania are discussed in depth e.g. by Ivasiuc (Ivasiuc 2014).

We found that many of the HMP fieldworkers spontaneously incorporated most of the SDH lacking in the HMP theory (see Table 6.2) into their everyday implementation of the program. This finding corresponds with and significantly extends existing indices of similar positive potentials in most of the other HMPs (JSI 2006; OSF 2011; OSI 2005; WHO 2013b). In contrast with the other HMPs in CEE, the evaluated HMP seemed to exhibit unparalleled capacities especially with respect to the structural SDH, and this apparently was mainly through the HMP coordinator role (see Table 6.2). It thus seems that, importantly, while the fieldworkers in the CEE HMPs often deliberately appropriate their assigned duties, they typically do so to increase their own impact regarding SDH rather than solely for their private benefit. Also, the identified capability of the HMP fieldworkers to shift the actual intervention of the program successfully towards the more "upstream" SDH might present another indicator of the HMP leaders' genuinely collaborative approach to participation (see also the low-threshold hiring criteria and managerial support regarding issues raised by assistants beyond the program theory) (Hickey et al. 2004; Merzel et al. 2003). Creating more capacity in the HMPs for addressing SDH more extensively, e.g. through strengthening of positions, such as those of the coordinators, could thus greatly improve the overall impact of the HMPs regarding SDH.

We found that the HMP central management did not attempt to exploit the fieldworkers' interest and capacities with respect to SDH mainly due to their viewing the institutional environment in which the HMP operated as generally hostile. This sadly fits with all of the above-cited reports' long-term, and long-term ignored, key recommendations appealing to policy-makers to end the devastatingly precarious status of HMPs in CEE (JSI 2006; OSF 2011; OSI 2005; WHO 2013b). For analogous findings regarding community health-workers in general, see Lehmann and Sanders's 2007 review (Lehmann et al. 2007).

In addition, we found that the decidedly negative attitude of central managements regarding the possibility of extending the HMP with SDH agendas devoted specifically to the socio-political context was based on viewing such agendas as being beyond the realm of health. This finding matches the observations that health-promotion practice is everywhere

still mostly conceived of according to the individual-level factors-rather than to the SDH paradigm (Labonte et al. 2008; McQueen et al. 2007; Merzel et al. 2003). To overcome these hindrances at the managerial level, greater institutional support of the HMPs by external actors and closer cooperation between the HMPs leaders and experts in public health thus seem indispensable.

6.5.1 Strengths and Limitations

The key strength of our research dwelled in the long-term personal embeddedness of the corresponding author within the examined HMP across its organizational levels. In addition, most of the long-term observations and elicitations took place in a geographical area where and among people with whom the corresponding author has previously lived as an ethnographer. These circumstances, in combination with our systematic encouragement of the respondents' critical feedback, made it possible to obtain data of unusual depth, and robustness.

The main limitations of our research were due to the purposefully chosen qualitative strategy. Seeking well-grounded insights into the HMP's everyday potentials via long-term personal embeddedness among only some of its participants and recipients, we could not deliver findings readily representative of the whole program. Also, for logistical reasons we did not manage to obtain data on perspectives of other actors involved in the HMP practice, such as representatives of local authorities or healthcare providers. Lastly, we faced the tactics that respondents used to curb the imagined and real power asymmetries between themselves and other research participants (e.g. in all respondent groups we experienced initial distrust and follow-up adjustments of responses). The first author's long-term personal presence and encouragement of critical feedback might have limited power-related biases. However, our exploratory findings do require further confirmation.

6.5.2 Conclusions

Unlike in its theory, in its everyday implementation the evaluated HMP addressed most known SDH. Reports indicate that similar discrepancies between theory and practice occur in other CEE HMPs. To increase the impact of HMPs on SDH, their theories and procedures should be adapted according to the programs' more promising actual practice regarding SDH. To enable this, we advise closer cooperation between the HMPs' leaders and public health experts and an increase of the HMPs' institutional stability.

Annex 6.1 The original evaluated health-mediation program's documentation included in the data for analysis

Descriptions of the program theory and practice	osvety zdravia] (2014, 2015)
Project Healthy Communities – Description of the Healthy Communities project [Projekt Zdravé komunity - Popis projektu Zdravé komunity] (2013)	Recruitment forms Health edification assistant questionnaire [Dotazník pre asistentov/ky osvety zdravia] (2014)
Healthy Communities – Final report [Zdravé komunity Závěrečná správa] (2014)	Coordinator of the Health edification assistants questionnaire [Dotazník pre koordinátorov asistentov osvety zdravia] (2014)
The statute of the association of legal entities Platform for promotion of the health of disadvantaged groups [Stanovy občianskeho združenia Platforma pre podporu zdravia znevýhodnených skupín] (2014)	Curriculum form [Formulár Životopis] (2014)
National project 'Healthy Communities' proposal [Zámer národného projektu Zdravé komunity] (2014, 2015)	Training documentation and materials The health edification assistant role [Úloha asistenta zdravotnej osvety] (2014)
Project Healthy Communities Application Appendix 1 – Project description [Žiadosť o poskytnutie nenávratného finančného príspevku Príloha 1 – Opis projektu] (2014, 2015)	Care for pregnant women and new-borns [Starostlivosť o tehotné ženy a novorodencov] (2014)
Job specification for the Health edification assistant role [Pracovná náplň Asistenta osvety zdravia] (2014)	Human biology basics [Základy biológie človeka] (2014) Epidemiology [Epidemiológia] (2014)
Job specification for the Coordinator of the Health edification assistants role [Pracovná náplň Koordinátora asistentov zdravotnej osvety] (2014)	Basic communication skills for work with in the Roma communities [Základné komunikačné zručnosti v práci s rómskymi komunitami] (2014)
Health edification assistant role activity sheets [Pracovné výkazy asistentov]	Specialized social counselling with respect to health care [Špecializované sociálne poradenstvo v oblasti zdravotníctva] (2014)

Annex 6.2 Semi-structured interviews outline

The program participation in the context of the participant's life	specific bodily characteristics, and access to healthcare)? How?
How did your life change after you took up your position within the program (explain the positives and negatives)?	Do you think enough attention is paid in the program set-up to whatever else might be contributing to the worse health in the segregated communities (e.g. education, occupation, income, gender roles, and incidents of racism)? How?
What do you like / don't like about your current job?	
Personal account of segregated Roma health status	Do you think the program is well set-up to positively influence whatever might be affecting the health in the segregated communities at the country level (e.g. how these issues are governed centrally, particular related policies, the wide-spread anti-Roma racism) How?
Do you think there are differences in health between the Roma and the non-Roma? Based on what?	
If so, where do you think these differences come from? Based on what?	Personal account of the program practice
What do you think could be done in order to alleviate these differences? Based on what?	Which of its goals is the program successful at achieving? How come? Based on what do you think that?
Personal account of the program theory Why did the program start and who started it? Using what money? Where do you know this from?	Which of its goals is the program unsuccessful at achieving? How come? Based on what do you think that?
What does the program management claim it wants to achieve? What do you think the program management wants to achieve in reality? Where do you know these things from?	Do you think the program is successful at dealing with whatever damages people's health directly (e.g. material conditions, circumstances causing stress, risky health behaviours, specific bodily characteristics, and access to healthcare)? In what in particular? Based on what do you think that? What else should be done in this area and what should be done differently? Why?
How do you think the management wants to achieve these things? Where do you know this from?	
Do you think the program should focus on and should be doing something else as well? Why?	
Do you think enough attention is paid in the program set-up to whatever damages people's health directly (e.g. material conditions, circumstances causing stress, risky health behaviours,	Do you think the program is successful at dealing with whatever else might be contributing to the worse health in the segregated communities (e.g. education, occupation, income, gender roles, and incidents of racism)? In what in particular? Based on what do

you think that? What else should be done in this area and what should be done differently? Why?

Do you think the program is successful at positively influencing whatever might be affecting the health in the segregated communities at the country level (e.g. how these issues are governed centrally, particular related policies, the wide-spread anti-Roma racism)? Based on what do you think that? What else should be done in this area and what should be done differently? Why?



Chapter 7

Do Roma and non-Roma patients need different care?

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7.1 Introduction

As researchers regularly publishing on Roma health in Slovakia and beyond, we often get approached by alerted clinical practitioners who treat Roma patients. Usually, they contact us with the impression that their Roma and their non-Roma patients have significantly different symptoms, morbidity or care outcomes. How should practitioners approach such apparent differences? Fellow researchers elsewhere in Central and Eastern Europe (CEE) are likely to face similar requests for help (Cook et al. 2013; Crowe 2007).

Here we offer a step-by-step guideline for dealing with such seeming differences. However, as the practitioners approaching us most often suspect major genetic influences, we will start with brief reiterations of why genes are the least and social determinants the most reasonable suspects to begin investigation with in this and in similar cases.

7.2 Why should genes come last?

To expect major genetic influences behind ethnic health disparities is unreasonable according to the principles of population genetics. Any population genetically more predisposed for a range of health problems should have been previously selected systematically, whether naturally or intentionally, for the unhealthy predispositions. This is a highly unlikely proposition regarding any social group (Diez Roux 2012; Haydon 2007; Yudell et al. 2016).

Accordingly, and alike for other ethnic health-disparities (Diez Roux 2012; Dressler et al. 2005), the insignificance of genetic influences behind poor Roma health status has been confirmed empirically. The only genetic susceptibilities identified in Roma are higher frequencies of a handful of gene-alleles causing rare diseases, peaking in some localities due to total social (reproductive) segregation from neighbouring

populations (Diószegi et al. 2017; Fiatal et al. 2016; Kalaydjieva et al. 2001; Martinez-Cruz et al. 2016). Let's emphasize that this is despite a previous disproportionate focus of research specifically on possible genetic influences (Hajioff and McKee 2000; Zeman et al. 2003).

7.3 Why should social determinants come first?

According to epidemiological theory, social health disparities are almost always established and maintained socially. There are many other common ways for human bodies to get damaged beyond the above discussed genetic susceptibilities to diseases, ranging from unfavourable material living conditions and risky health-related practices to stress. Health disparities between social groups are typically determined through socially maintained distinct combinations and the interplay of all such exposures over the life-course (Diez Roux 2012; Krieger 2011; WHO 2010a).

Like for other major ethnic health disparities (Bailey et al. 2017; Bhopal 2015; Dressler 2010), empirical evidence on CEE Roma health-disparity fits the epidemiological theory well. Over the last ten years research has shown that most of this disparity, too, can be explained by socially disadvantaged segments of the worse-off population disproportionately facing a wide range of environmental, behavioural, psychological and care-related exposures over the life-course (e.g. Arora et al. 2016; Cook et al. 2013; EUC 2014; Geckova et al. 2014; Masseria et al. 2010).

Thus, any clinical discrepancies between Roma and non-Roma also most likely originate from, are maintained by, and can be alleviated via adjustments of social processes supporting unequal exposures over the life-course. Different exposures can and do get embodied across ethnic divides – they then become biology (Bailey et al. 2017; Bhopal 2015; Gravlee 2009). However, as such differences only present the results of social differences, the tackling of their adverse clinical outcomes should start with assessing the underlying exposures and related social processes.

7.4 Guideline

Drawing on the above and related experience, we suggest the following approach (see also Figure 7.1):

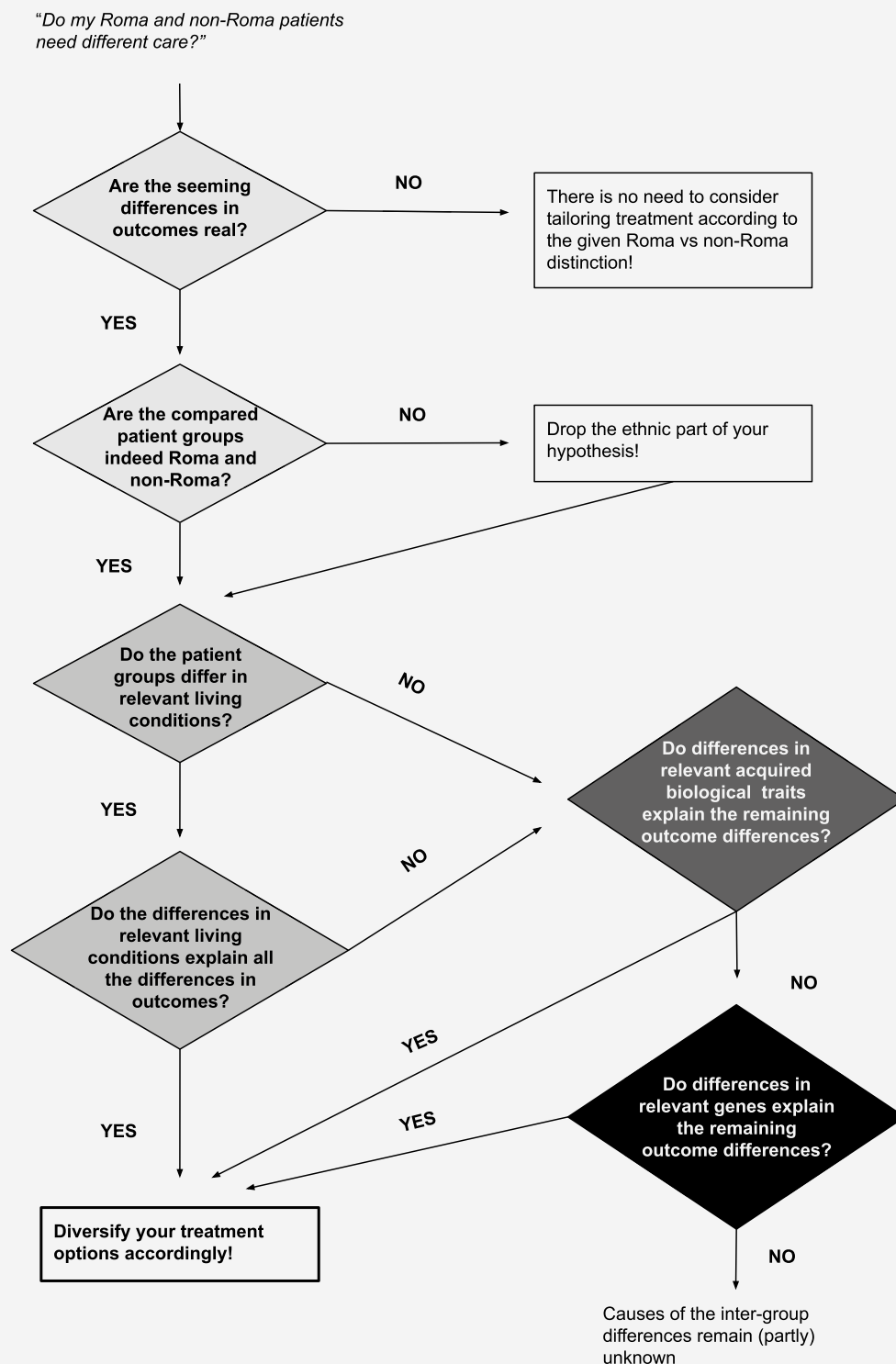


Figure 7.1 A step-by-step guideline for dealing with apparent differences in Roma and non-Roma patients

Do Roma and non-Roma patients need different care?

1) Are the seeming differences in outcomes real?

Do the studied differences remain statistically significant after adjustments for likely differences in the demographics of the different populations the compared patient groups are supposed to represent?

- Until this question can be answered “yes”, patients considered to be Roma and non-Roma should not be treated differently.

2) Are the compared groups indeed Roma and non-Roma?

Do all patients in both groups agree to being labelled as such according to a set of unambiguous criteria? Ethnicity labelling can be constructed and contested in many ways by both those labelled and those labelling (Janka et al. 2018; Ladányi et al. 2001).

- If “no”, drop the ethnic part of the hypothesis but continue with the next step (3).
- If “yes”, specify the ethnic aspect of your hypothesis (e.g. what kind of Roma?) according to the identification criteria used and continue with the next step (3).

3) Do the patient groups differ in relevant living conditions?

Do available databases or follow-up communication with the patients indicate that the compared groups face living conditions that are distinct in aspects which might relate to the studied differences in outcomes?

- If “yes”, continue with the investigation of possible causes related to living conditions (4).
- If “no”, continue with the investigation of possible acquired biological causes (5).

4) Do the differences in relevant living conditions explain all the differences in outcomes?

Do all the studied differences in outcomes between the compared patient groups disappear after statistical adjustments for the differences in relevant aspects of the groups’ living conditions?

- If “yes”, try to develop and propose specific treatment plans that also account for the found influences of living conditions
- If “no”, continue with the investigation of possible acquired biological causes (5).

5) Do differences in relevant acquired biological traits explain the remaining outcome differences?

Does additional clinical testing show that the compared groups might have acquired different biological traits, which might relate to the studied outcomes?

- If “yes”, try to develop specific treatment plans that account for the found influences of acquired biological differences
- If “no”, continue with the investigation of possible genetic causes (6).

6) Do differences in relevant genes explain the remaining outcome differences?

Does additional clinical testing show that the compared groups have genetic variants which might relate to the studied outcomes?

- If “yes”, try to develop and propose specific treatment plans that account for the found influences of genes
- If “no”, you were not able to identify some of the causes behind the existing differences, sorry.

7.5 Conclusion

We have herein proposed and justified a step-by-step guideline for dealing with apparent clinical differences in Roma and non-Roma patient groups. The guideline recommends that clinical practitioners facing such differences take a specific route. This route starts with assessing the statistical significance and representativeness of the difference through clarification and legitimization of ethnicity criteria, then goes on to assessment of differences in relevant living conditions, and only arrives at assessing biological differences if refuting the preceding.

Chapter 8

Discussion

The general aim of this thesis was to improve the understanding of health inequalities between segregated Roma and the general populations in Central and Eastern Europe (CEE) by exploring related views and practices of segregated Roma and health-system professionals in Slovakia by exploring FIRST related views and practices of segregated Roma and THEN OF health-system professionals in Slovakia. More specifically, we aimed to explore everyday practices and perspectives regarding three pathways that may contribute to this inequality: the pathways between Roma practices and health outcomes within segregated Roma enclaves, the pathways between health-system frontline services and segregated Roma affecting exposures of the Roma, and “upstream” determinants affecting both of the above pathways (see Figure 8.1). We start this chapter with a review of the main findings from each of the research questions addressed in the thesis. Next, we discuss what these findings add to the existing CEE evidence regarding the specific pathways the thesis focused on and formulate overall findings with respect to its general aim. We then summarize the strengths and limitations of the ethnographic toolkit we used to obtain the findings. Subsequently, we list the implications of the thesis for practice, policies and research addressing health inequalities between segregated Roma and the general populations in Slovakia and elsewhere. We end with some brief conclusions.

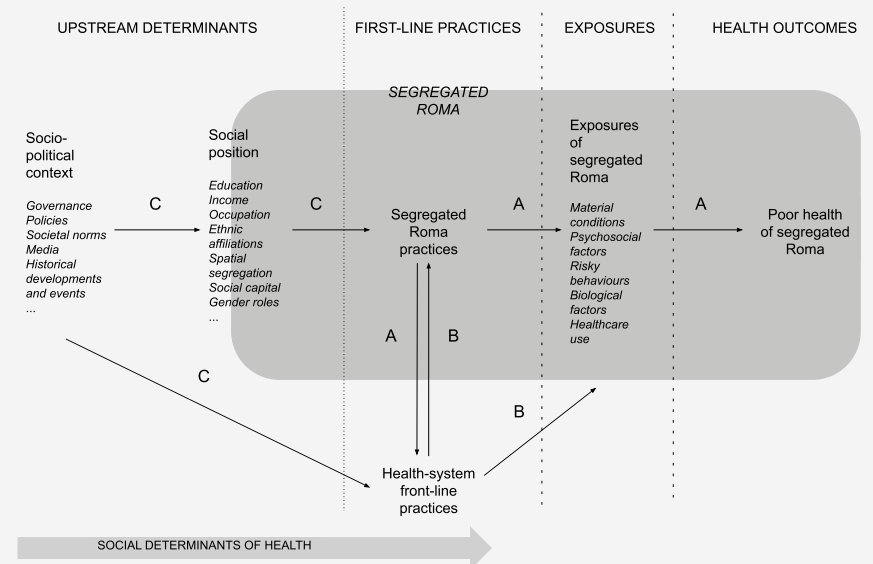


Figure 8.1 Pathways discussed
Discussion

8.1 Main findings

RQ1) What health-endangering settings and practices do segregated Roma face and engage in over the long-term in Slovakia?

We explored over 10 years the health-endangering everyday settings and practices in a segregated rural Roma settlement in Slovakia. We found that for all the examined dimensions – material circumstances, psychosocial factors, health-related behaviours, social cohesion and healthcare utilization – all the settlement's residents faced a wide range of health-endangering settings and practices. How the residents engaged with and within some of these exposures and how these exposures affected their health varied according to local social stratifications. Material circumstances and perceived stressors varied the most, with the latter including some unusual and lacking some common stressors. Most identified patterns did not change over the decade, and the overall health gap from local non-Roma seemed to prevail.

RQ2) Why don't segregated Roma in Slovakia themselves do more for their health?

Within the same segregated Roma settlement, we simultaneously explored local-level mechanisms supporting segregated Roma nonadherence to clinical and public health recommendations. We identified six such mechanisms: the Roma situation of poverty, segregation and substandard infrastructure; the perceived value of Roma alternative practices; exclusionary non-Roma and self-exclusionary Roma ideologies; discrimination, racism and dysfunctional support towards Roma by non-Roma; drawbacks in adherence; and Roma socialization into their situation. We found that these mechanisms formed an inter-locked system controlled by and operating through both local Roma and non-Roma.

RQ3) Why don't healthcare frontliners in Slovakia do more for segregated Roma?

We assessed the practices of healthcare frontliners regarding segregated Roma in Slovakia, mechanisms supporting substandard practices and the frontliners' resilience to such mechanisms. We found that frontliners' substandard practices mostly involved substandard communication and care commitment, but also overt ethnic discrimination. This outcome was supported by five mechanisms: frontliners' negative experiences with "problematic Roma patients"; frontliners' negative attitudes regarding segregated Roma; adverse organizational aspects; adverse Roma-segregation aspects; adverse societal-level influences. Over their careers, frontliners who started without negative attitudes towards segregated Roma patients

first felt obliged and trying, then failing, unequipped and abandoned, and ultimately frustratingly resigned regarding an equal standard of care.

RQ4) How well do health-mediation programs address the determinants of the poor health status of segregated Roma?

We evaluated how known social determinants of health (SDH) were addressed in the agenda and in the everyday implementation of a national health-mediation program (HMP) addressing segregated communities in Slovakia. We found that in its agenda, the HMP addressed only health-related behaviours and healthcare access and set its goals regarding the latter in a way discouraging positive changes in the former. In the everyday implementation of the HMP, healthcare access facilitation activities appeared to be effective, well received by the HMP recipients and assistants and performed as set out by the latter. The opposite was true for most educational activities targeting health-related behaviours. The HMP fieldworkers were proactive and sometimes effective at addressing SDH domains beyond the HMP agenda. The HMP leaders supported such engagement only informally, finding the program inadequate and too unstable to handle any such extensions.

RQ5) Do Roma and non-Roma patients need to be treated differently in clinical practice?

Based on some of the above findings and a literature review, we designed a step-by-step guideline for dealing with apparent clinical differences in Roma and non-Roma patient groups in the clinical practice. The guideline recommends that clinical practitioners facing such differences start by assessing the statistical significance and representativeness of the difference through clarification and legitimization of ethnicity criteria, then assess differences in relevant living conditions, and assess biological differences only if refuting the preceding.

8.2 Discussion of the main findings

Here, we first discuss what the above main findings add to the existing CEE evidence regarding the three kinds of pathways this thesis focused on, as shown in Figure 8.1: A) pathways between Roma practices and health outcomes within segregated Roma enclaves, B) pathways between health-system frontline services and segregated Roma affecting exposures of the Roma, and C) "upstream" determinants affecting both of the above pathways. Next, we formulate overall findings.

8.2.1 A) *Exposure patterns and practices within segregated Roma settlements*

We found that in some segregated Roma settlements in Slovakia household material circumstances improved significantly with increasing household social status, while health-related behaviours, healthcare use and health problems remained nearly equally poor. The patterning of material conditions, health-related behaviours and healthcare use within any segregated Roma enclaves have so far not been studied elsewhere in the CEE. Our findings, nevertheless, match well with and provide a new alternative explanation for the then surprising findings by Geckova et al. (2014) of health status not significantly improving with increasing SEP within segregated Roma settlements in Slovakia. Also, these findings are in line with results from extensive surveys indicating variability in material circumstances, healthcare use and self-rated health within Roma settlements in Slovakia (Filadelfiova 2013a; Filadelfiova 2013b; Filadelfiova et al. 2012) and elsewhere in the CEE (UNDP 2012). Our findings thus confirm that material circumstances, health-related behaviours and healthcare use are significant exposures that disproportionately damage the health of the CEE segregated Roma (EUC 2014; UNDP 2012); they also enrich this picture by showing that and how some of these exposures might vary within segregated Roma enclaves and to what effects.

We found that in some segregated Roma settlements in Slovakia, several standard stressors were not as common as elsewhere or not experienced as such, and a few stressors varied in significance with the households' changing social status. Stressors and stress patterns of segregated Roma have thus far not been studied elsewhere in the CEE. However, our findings are congruent with previous findings of both significant psychosocial pressures and specific coping strategies regarding standard stressors for CEE segregated Roma, although some regional differences may exist (Bobakova et al. 2015; Bobakova et al. 2012; Čvorović et al. 2018; Davidova et al. 2010; Dimitrova et al. 2014; Dimitrova et al. 2018; Dimitrova et al. 2017; Kamberi et al. 2015; Kolarcik et al. 2010; Kolarcik et al. 2012). In line with common findings regarding ethnic health inequalities elsewhere (Bailey et al. 2017; Dressler et al. 2005), our findings thus suggest that the so far understudied psychosocial pathways likely belong to the most important and the most context-dependent mechanisms contributing to the poor health of CEE Roma.

We found that in some segregated Roma settlements in Slovakia over the period 2004–2014 a few exposures have slightly changed for the better and several for the worse, making the overall gap in and conditions for health between the local segregated Roma and non-Roma

villagers seemingly to persist. No rigorous comparative longitudinal studies have been carried out on segregated Roma thus far, and current local surveillance systems do not allow for assessing trends in exposures and health in any Roma either (ERRC 2013; EUC 2014). The trend we observed, nevertheless, matches the trends shown in the extensive regional NGO surveys, as well as in scarce other studies (EUFRA et al. 2012; Sándor et al. 2017; UNDP 2012). Our findings thus support the notion that the gaps in health exposures and health status in CEE have not significantly decreased over the Decade of Roma Inclusion (EUC 2018a; Sándor et al. 2017) and indicate mixed changes in some of the underlying Roma exposures.

8.2.2 B) *Health-system frontline practices affecting exposure patterns of segregated Roma*

We found that in Slovakia, healthcare and health-mediation services insufficiently accommodated the poor health-related conditions of segregated Roma, sometimes deliberately. We also found that this exacerbated specific health problems in the Roma due to their resulting selective use of the services. Our findings fit with the available CEE evidence in showing the poor availability of and substandard frontline services towards segregated Roma, including overt ethnic discrimination and racism, and in showing how this can contribute to Roma using such services less and rating their health as worse (e.g. Andreassen et al. 2018; Andreassen et al. 2017; Arora et al. 2016; CRR 2017; Duval et al. 2016; Filadelfiova 2013b; Janevic et al. 2015; Janevic et al. 2017; Janevic et al. 2011; Kolarcik et al. 2015; Watson et al. 2017). Regarding health-mediation, no previous rigorous assessments are available. Our findings, nevertheless, match critical comments in reports on health-mediation, acknowledging that these interventions omit important determinants of health and sometimes become appropriated by the involved Roma as mere extra free resources for maintaining their status quo (e.g. JSI 2006; OSF 2011; WHO 2013b). Our findings thus confirm substantial insufficiencies in CEE health-systems with respect to segregated Roma, including discrimination and racism, and extend the picture with an example of how resulting selective use of frontline services might be specifically affecting the health of the Roma.

We found that many healthcare and health-mediation frontliners in Slovakia were proactively improvising, often effectively and sometimes beyond their job duties, to better accommodate or curb the poor health-related conditions of segregated Roma. However, they remained unable to improve the situation significantly. Our results resemble

findings from other studies examining similar themes, that identified extensive and partially effective anti-discriminatory improvisation among healthcare frontliners and health mediators in Romania (Schneeweis 2013; Wamsiedel 2018). However, our findings are also in accord with epidemiological evidence from elsewhere (Krieger 2011; WHO 2010a; WHO 2010b) showing that the root determinants of steep social inequalities lie beyond the access to and quality of services for people who are already sick. In sum, our findings indicate both motivation and knowledge among CEE health-system frontliners regarding how the health needs of segregated Roma might become better accommodated within the frontline practices but also confirm that such practices alone are unlikely to tackle the whole health gap.

8.2.3 C) Upstream determinants of the identified patterns in health-system and Roma practices

Social mechanisms supporting practices within segregated Roma enclaves

We found that in Slovakia some segregated Roma partly shared local non-Roma views claiming natural Roma incapacities. We also found that this view of incapacity constituted a 'cause behind the cause', i.e. a factor leading to a series of further effects, including supporting the Roma in their deliberate nonadherence to biomedical recommendations. Our findings match the observations (Janevic et al. 2011) of racist non-Roma views undermining the confidence of segregated Roma to use healthcare. Newly, our findings add to this that racist ideas regarding Roma can also inspire and support Roma nonadherence, which is then expressed as a proud ethnic preference, especially through Roma socialization that leads to the incorporation of such ideas (cf. Crondahl et al. 2012; Kelly et al. 2004). These findings complement indices of distinctive ethnically framed CEE Roma identities (e.g. Dimitrova et al. 2014; Dimitrova et al. 2018) and social strategies (e.g. Čvorović 2004; Čvorović et al. 2018) with respect to health. They also align with ethnographic studies that consistently show excluded Roma to proudly, and often "naturally", develop solutions to practical problems preferably outside local non-Roma social norms and institutions (e.g. Brazzabeni et al. 2015; Engebriksen 2007; Gay Y Blasco 1999; Okely 1983; Stewart 1997; Tauber 2006; Tešar 2012; Williams 2003). Our findings support the notion that context-dependent socialization patterns are key social mechanisms underlying health inequalities at the behavioural level (Cockerham 2005; Frohlich et al. 2001; Singer et al. 2016; Singh-Manoux et al. 2005). They add that

racist ideas on Roma might divert CEE segregated Roma from available biomedical recommendations and services by inspiring and supporting ethnically framed countercultural Roma socialization and attitudes (Binkley 2007) towards such care standards.

Social mechanisms supporting health-system frontliners' practices towards segregated Roma

We found that in Slovakia the substandard practices of both healthcare and health-mediation frontliners with respect to segregated Roma were supported by the lack of organizational support for handling structural vulnerabilities of their clients and by racism and related professional expectations. We also found that in the case of healthcare frontliners, this often resulted in gradually becoming cynical regarding Roma patients. Our findings match scarce previous related studies showing similar difficulties and outcomes among both kinds of frontliners addressing segregated Roma in Romania (Schneeweis 2013; Wamsiedel 2018). Our findings are also in line with research on factors contributing to and consequences of healthcare staff burnout in general (Glasberg et al. 2007; Hall et al. 2016; Rose et al. 2017). In sum, our findings add that the generally understudied poor organizational support of CEE health-system frontliners is likely to be a key mechanism that leads to poorer care practices regarding segregated Roma in the region.

We found that in Slovakia, health-system frontliners who were more familiar with the current history, conditions and practices of segregated Roma were more resilient to the mechanisms supporting substandard practices regarding segregated Roma. Resilience of health-system frontliners is generally understudied (Glasberg et al. 2007; Gronholm et al. 2017; Hall et al. 2016). However, our findings are in line with socio-psychological research on discrimination showing that greater intergroup contact, in general but especially when positive, tends to decrease negative attitudes (Kauff et al. 2017; Pettigrew 2016). Our findings also match recommendations for interventions specifically addressing ethnic inequalities in care (Bailey et al. 2017; Griffith et al. 2007; van Ryn et al. 2011) and also match the expectations of the classics of anti-racism (Allport 1979; Lévi-Strauss 1952). Thus, our findings add that CEE health-system frontliners might become psychologically fitter for serving regional segregated Roma if equipped with a better understanding of the mechanisms driving current conditions and practices of the Roma.

Societal-level influences supporting the identified social mechanisms

We found that the omnipresence of racialized ideologies on Roma and poor organizational support towards segregated Roma were sustained by a general lack of evidence-based understanding of current segregated Roma conditions and practices. There is increasing evidence on the influences of racism across health-systems with respect to segregated Roma in the CEE region (Janevic et al. 2017; Janevic et al. 2011; Stojanovski et al. 2019). However, we found no previous studies on what supports the omnipresence of antigypsyism in CEE health-systems. Our findings are, nevertheless, in line with those from other studies indicating the potential of positive inter-group contact in decreasing anti-Roma attitudes in the region (Kamberi et al. 2017; Kende et al. 2017a; Kende et al. 2017b; Visintin et al. 2017). Our findings also complement recent critiques of pro-equity efforts omitting antigypsyism (Albert et al. 2016; EUC 2018a; EUC 2018b; McGarry 2017; Stewart 2012; Vermeersch et al. 2017). They add that seeking and society-wide dissemination of intelligible evidence-based explanations of current conditions and practices of specific segregated Roma might improve the health of Roma.

We found that in Slovakia poor organizational support of health-system frontliners with respect to segregated Roma was sustained by poor (and declining) commitment regarding the known social determinants of health (SDH) among the health-system managers. How health-systems in CEE incorporate recommendations regarding SDH with respect to segregated Roma has not been previously assessed systematically (Koller 2010; WHO 2013a). However, our findings are consistent with those on the general difficulties of health-systems to successfully implement SDH frameworks (Bambra et al. 2010; Carey et al. 2015; Garthwaite et al. 2016), as well as with literature noting a gradual dismantling of public health infrastructures with exceptional historical records regarding SDH in the region (Kringos et al. 2013; Tulchinsky et al. 2014). Our findings thus suggest that (re)equipping regional health-system managers with state-of-the-art SDH-related tools and targets might increase positive impacts of the health-systems on the poor health of segregated Roma in the region.

8.3 Overall findings

The findings we have discussed provide new explanations for the poor health status of segregated Roma compared to the general population

in Slovakia. In this section, we will summarize these explanations via four simple explanatory routes.

8.3.1 Antigypsyism is omnipresent and a fundamental cause

The first explanatory route is that antigypsyism, i.e. ideas considering the capacities of segregated Roma partly low naturally (Albert et al. 2016), adversely contributes to all the pathways leading to poor health status of the Roma we studied in Slovakia, including those apparently controlled by the Roma themselves (see Figure 8.2). Moreover, the effects of the thus omnipresent anti-Roma racism at the “upstream” levels seem to match the criteria for a fundamental social cause driving ethnic health inequalities, as defined by Phelan et al. (2015). Namely, the antigypsyism in Slovakia, too, appears to disproportionately obstruct this ethnic group from accessing flexible societal resources important for health, such as SEP, community infrastructure and access to services. Consequently, the Roma become continuously diverted disproportionately from effective management of health risks and resources in Slovak society regardless of how the particulars of such risks and resources change over time.

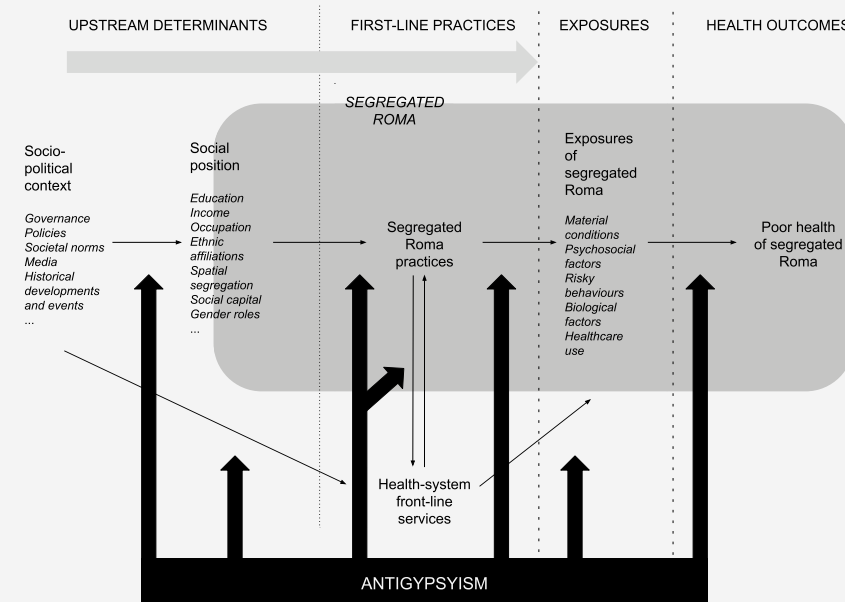


Figure 8.2 Omnipresent influence of degrading racialized ideologies on Roma

8.3.2 Countercultural Roma adaptations to antigypsyism and their mixed consequences

The second explanatory route is that in some segregated Roma settlements in Slovakia people adapt to the omnipresent racist anti-Roma ideas and their negative consequences by partially incorporating these ideas into their own ethnically framed racialized ideologies considering outside norms as unsuitable for Roma naturally. We also found that such an understanding of Roma ethnicity by the Roma themselves bears mixed consequences with respect to their health. On the one hand, it decreases the interest and ability of the Roma to positively experience and use available biomedical knowledge and services. On the other hand, it motivates the Roma to proactively experiment with development of approaches to care alternative to locally available biomedical recommendations and services as well as to experience the former often as superior. Countercultural social norms among oppressed people have been shown to support the development of care practices favourable to health according to biomedical criteria, such as less medicalised care (e.g. Conrad 2007; Foucault et al. 2007; Illich 1982; Lock et al. 2010; Merrild et al. 2017; Rabinow et al. 2006; Whyte 2009). Health-related practices of CEE segregated Roma might therefore present a valuable empirical resource regarding possible drawbacks in local biomedical practice (see Figure 8.3).

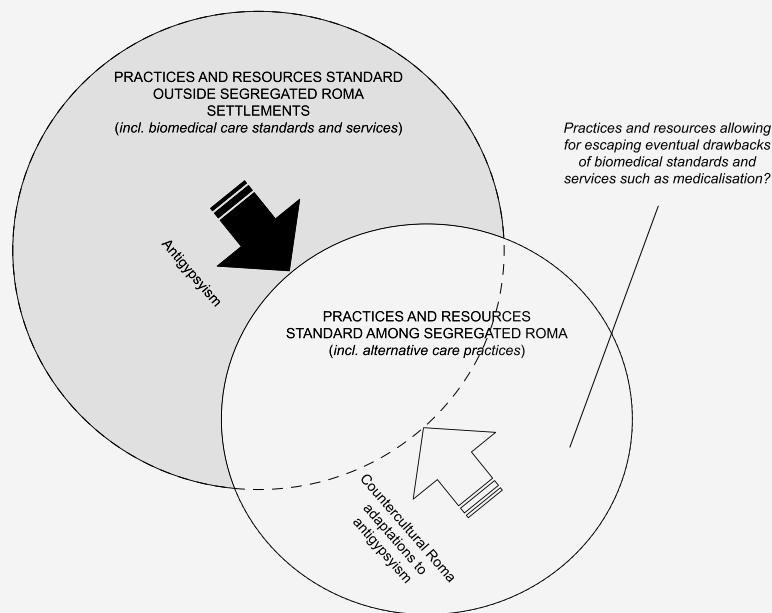


Figure 8.3 The effects of antigypsyism and related Roma social adaptations on the nature of Roma care practices

8.3.3 Countercultural trade-off mechanisms patterning exposures in segregated Roma settlements

The third explanatory route is that in some segregated Roma settlements in Slovakia, countercultural ethnic ideologies, i.e. ideologies considering outside “non-Roma” norms as inappropriate for Roma, work as a mechanism supporting inside patterning in health-related resources and exposures according to the social status of households in a trade-off manner. An increasing of social status within the settlements is associated with (and demonstrated by) better access to some outside resources but at the same time decreases acknowledged “proper Roma” status and related local resources. Moreover, especially people from high status households are at a constant risk of losing their Roma status and related resources altogether as their ways of life become so close to the outside standards that they become considered “too non-Roma like” (*gadžikane*). This can lead to denial of their ethnic identity, and social isolation with related adverse psychosocial consequences (see Figure 8.4).

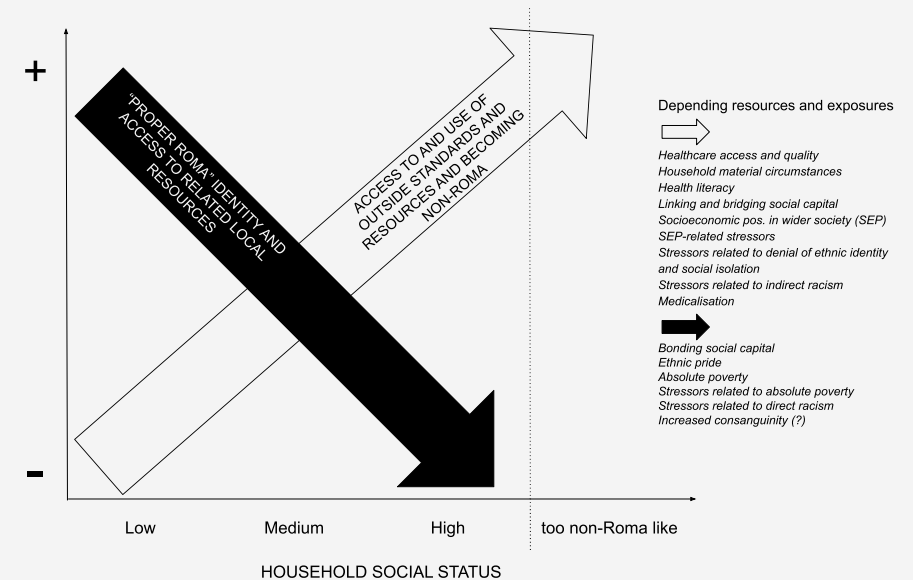


Figure 8.4 Ethnically framed countercultural trade-off mechanism within segregated Roma enclaves patterning health exposures

8.3.4 Poor understanding of segregated Roma hinders their effective use of services

The fourth explanatory route is that in Slovakia, a generally poor understanding of the current conditions and practices of local segregated Roma sustains organizational features of health-system services that support substandard frontliners' practices towards the Roma, which in turn also discourages Roma from using the services. Reflecting the societal norm, all healthcare professionals consulted had views regarding segregated Roma that included confused and racist explanations that lacked rigorous historical, ethnographic and sociological evidence. This maintained several organizational features that supported substandard frontliners' practices towards segregated Roma: the lack of explicit commitment of managements regarding equal care for segregated Roma; the lack of clear operating procedures and training regarding non-compliance of vulnerable people; the lack of intelligible evidence-based information on the conditions and practices of local segregated Roma; the lack of Roma staff; and unrealistic expectations regarding the positive impact of the services on the health-status of segregated Roma (see Figure 8.5). This matches findings from studies informed by critical theories on indirect pathways of racism in care systems (Bailey et al. 2017; Feagin et al. 2014; Ford et al. 2010b; Hicken et al. 2018; Sue et al. 2007).

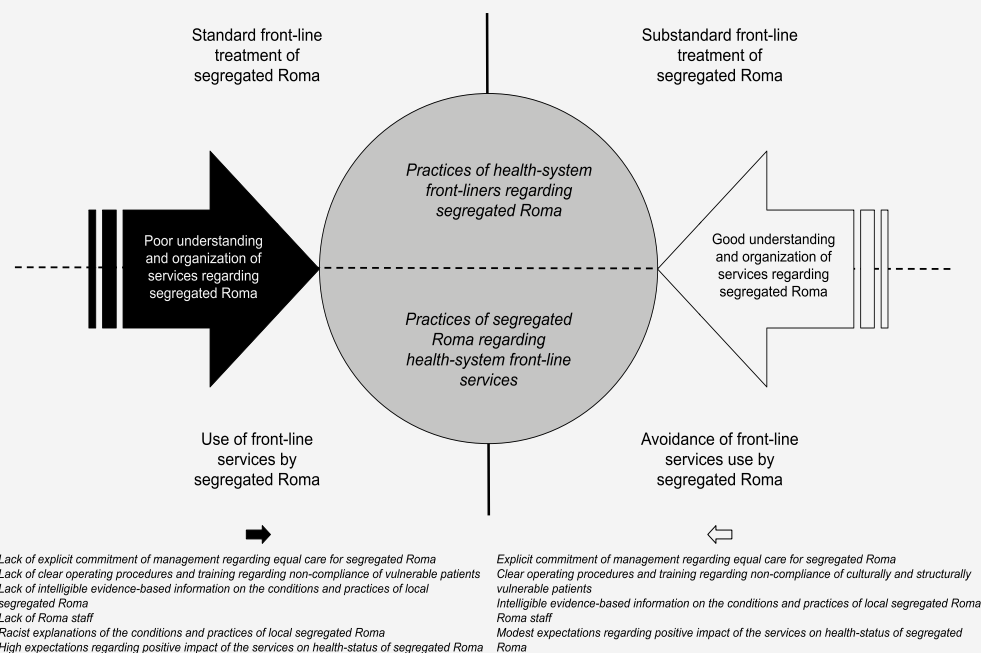


Figure 8.5 Effects and features of poor and good organizational accommodation of the conditions and capabilities of segregated Roma

8.4 Strengths and limitations

In general, our thesis's basic research design – a case study using ethnographic methods – seems to have enabled enriching the existing evidence on the drivers underlying the given health inequality, especially the drivers of the involved everyday practices. This is in line with the previous record of such designs, showing them capable of detecting and explaining influences on health traditionally called “cultural” (Napier et al. 2014; Singer et al. 2016; Trostle 2004). In this section, we will discuss in more detail the strengths and limitations of our design.

8.4.1 Quality of the samples

The main strengths of the thesis's sampling approach were its theoretically well-based purposive sampling of appropriate settings and of appropriate actors. To identify the kinds of actors worth studying with respect to the poor health of the segregated Roma in Slovakia, we used the WHO's Framework on the Social Determinants of Health (WHO 2010a), i.e. an ecological framework summarizing evidence on all known pathways underlying health inequalities (see also Figure 8.6). This enabled us to include the segregated Roma themselves and health-system professionals as populations that, indeed, had significant impacts. As the setting for the first two studies, we selected a rural segregated Roma settlement not extreme in any basic socio-geographic respects, according to a previously carried out national survey (Musinka et al. 2014). This enabled us to identify a segregated Roma setting rather typical for a large part of Slovakia. Within this setting, inspired by ethnographic “rapid assessment” procedures (Hausmann-Muela et al. 2003; Knoblauch 2005), we then used local social-level and family-affiliations criteria to stratify local households. By this, we were able to encompass local variability in health-endangering settings, practices and views in a sample of households for a closing systematic survey. In the second pair of studies, we followed standards of exploratory organizational research (McDonald 2005) and selected healthcare and health-mediation operations and professionals variables according to geographic, demographic and organizational criteria. These two samples both included consultants with wide ranges of different professional experiences.

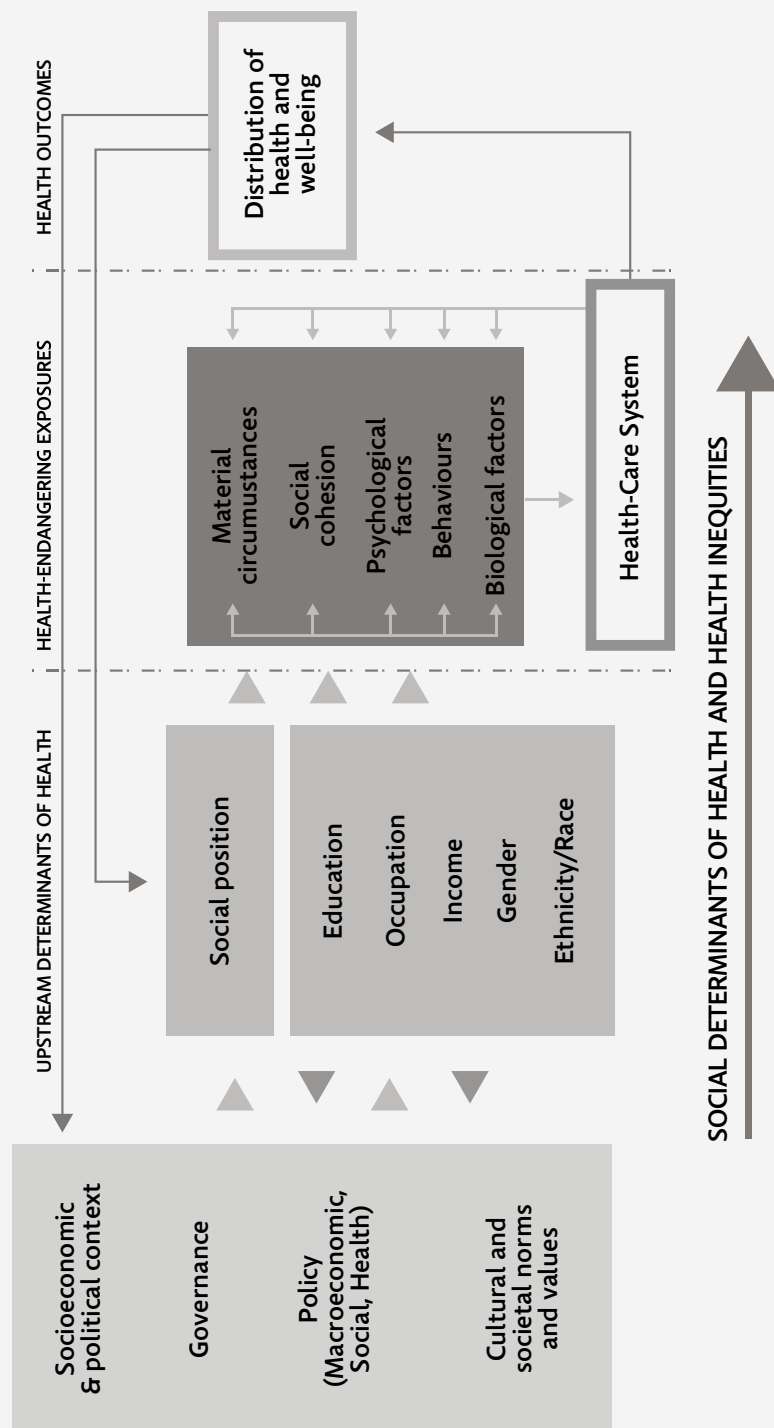


Figure 8.6 Conceptual framework on social determinants of health of the World Health Organization (derived from WHO 2010)

The main limitation of our sampling strategy was that our final samples were not statistically representative for Slovakia. This limitation, routine in any explorative qualitative research including ethnography (Flyvbjerg 2006; Gravlee 2011), could have limited the generalisability of our findings beyond the selected samples. However, our careful purposive selection approach may have compensated for this limitation well, given the good match of our results with other related findings for elsewhere in Slovakia and beyond.

8.4.2 Quality of the information

The main strength of our study design regarding the quality of the information lies in its well-theorized purposive uses of specific ethnographic principles and techniques. When approaching the everyday life of segregated Roma, we included an extensive initial ethnographic phase of participant observation, including learning of the Romani language, to account for both the lack of previous related data and our assumed mutual social distance (Hammersley et al. 2007). This enabled us to earn trust, gain access to and increase our understanding of rather unknown and intimate aspects of segregated Roma's views e.g. regarding Roma ethnicity. Similarly, long-term direct observations and personal rapport-building during job-shadowing (Czarniawska 2018; McDonald 2005) enabled us to gain novel kinds of data and the involved actors' views on relatively contentious issues regarding health-system frontliners everyday practices, such as racism. We continuously tried to reflect on and next to mitigate the unequal power relations between everybody involved, mainly through continuous reciprocal sharing of sensitive personal information and commitment to accurately critical yet personally safe public representation of the consultants' views (Christians 2005; Fassin 2013). This on many occasions led to our informants gradually sharing more candid, coherent and robust interpretations of their views and practices. The coherence and robustness of the information we obtained also gradually increased greatly thanks to continuous triangulation of all the data (Hammersley et al. 2007), especially by direct observations, open-ended follow-up discussions with all consultants as well as critical discussions of analyses and interpretations with the specific studies' co-authors.

The biggest limitation of our design regarding the quality of the information we gathered was the lack of inter-personal corroboration of direct observations and of the initial parts of the analyses. This limitation, standard in ethnography due to the logistic difficulty of sustaining long-term personal immersion of a greater number of researchers in

the field-work phases (Hammersley et al. 2007), could have biased our results according to the author's personal leanings and limitations. However, the above-mentioned reflective and triangulation features of the design are likely to have minimized this risk.

8.4.3 Causality

The biggest strength of the thesis design regarding causality consists in combining relational theories and data-acquisition techniques standardly used in ethnography. The use of structural-constructivist theories on human action (Archer 2000; Bourdieu 2000) enabled us to focus on the causal influences of both the specific settings of the studied practices ("structural constraints") and the meanings the involved actors attached to them ("social constructions"). The use of the ethnographic data acquisition techniques (Hammersley et al. 2007; Reeves et al. 2008) enabled us to obtain data rich enough to detect both these kinds of causal influences as happening in the everyday life of the studied actors.

The biggest limitation of our design regarding causality was that our data did not allow a linking of causes to outcomes other than via interpretation of the informants and that we could not test the identified causal relations statistically. This limitation is standard in exploratory qualitative research due to the logistic difficulty of securing rich data in sample sizes enabling meaningful counterfactual statistical analyses (Gravlee 2011). However, our final explanatory schemes fit most previous evidence on the causal pathways we explored. This means, that our combination of a well-chosen purposive sampling strategy, data-acquisition techniques and interpretation approach might have succeeded in overcoming the intrinsic uncertainties of case-study designs regarding causality (cf. Flyvbjerg 2006).

8.5 Implications

8.5.1 Healthcare

We found that a generally poor understanding of the current conditions and practices of segregated Roma can support substandard healthcare frontliners' practices towards the Roma (see Figure 8.5). We also found that apparent deliberate nonadherence of segregated Roma to clinical and public health recommendations (see Figures 8.3 and 8.4) belonged

among the least understood and the worst experienced Roma practices among the healthcare frontliners (see Chapter 5). These reasons for the poor healthcare treatment of segregated Roma and its negative effects on the use of healthcare services by Roma match most of the previous findings on indirect pathways of racism in care systems (Bailey et al. 2017; Feagin et al. 2014; Ford et al. 2010b; Hicken et al. 2018; Sue et al. 2007). Supporting CEE healthcare frontliners with skills and tools that help to prevent and mitigate such healthcare processes could therefore improve care for segregated Roma.

More specifically, CEE healthcare managements could provide their frontliners with training to help them understand racism, especially its indirect forms (Bailey et al. 2017; Mistry et al. 2009; Phillips 2011; van Ryn et al. 2011). Inclusion of intelligible evidence-based explanations of the current conditions and practices of local segregated Roma (EUFRA 2018a; EUFRA 2018b; Stewart 2013), apparently deliberate nonadherence in particular (see Figures 8.3 and 8.4), might increase the effectiveness of such training. Furthermore, segregated Roma patients might benefit from clearer care standards and operating procedures regarding healthcare frontliners' handling of culture-bound and structural vulnerabilities of patients (Bourgois et al. 2017; Hansen et al. 2016; Kleinman et al. 2006; Mistry et al. 2009; Sue et al. 2007). Next, the existing healthcare front-line tensions might also be mitigated by involvement of Roma health mediators (OSF 2011; WHO 2013b) and the employment of more Roma clinical professionals wherever possible (Bailey et al. 2017; Gronholm et al. 2017) (see also Chapter 6 of this thesis). Lastly, in order to prevent deception and burnout of healthcare frontliners, their managements could try to help them better manage professional expectations regarding care equity (Glasberg et al. 2007; Hall et al. 2016; Rose et al. 2017).

8.5.2 Public health

We found that CEE public health activities addressing poor Roma health, i.e. state public health activities and Roma health mediation programs, poorly accommodate the known social determinants of ethnic health disparities and existing potentials to influence such determinants. This hinders the greater positive contributions of such activities to the health of the Roma. To increase the positive contributions, the initiatives' managements could therefore try to make better use of current related evidence and recommendations (Bailey et al. 2017; EUFRA 2018b; Phelan et al. 2015; Phillips 2011; WHO 2013a). In general, this would mean addressing the poor health of the Roma as an outcome maintained via ethnic disparities in social determinants controlled across societal levels

and governance sectors (Brown et al. 2013; Carey et al. 2015; WHO 2013a) and significantly affected by a general antigypsyism (EUFRA 2018b) (see also Fig 8.2).

More specifically, national surveillance systems could begin with the collection and evaluation of data on Roma health-status and its likely determinants, i.e. data allowing for disaggregation according to ethnicity and for assessment of the levels of, at minimum, residential segregation and discrimination (cf. ERRC 2013; EUC 2014). Further, public health authorities could align their intervention and prevention activities with available Roma health mediation programs more strongly. This may increase the overall effectiveness in targeting of determinants of health at the community level, i.e. directly within segregated Roma enclaves. Roma health-mediation programs could increase their positive impacts based on adopting standard 'needs assessment → intervention adjustment → impact evaluation' cycles regarding all relevant social determinants of health, i.e. also beyond health-related behaviours and healthcare access (EUC 2012; Kelly et al. 2015; Ross 2006; WHO 2001). In this way, a more effective cycle of monitoring and subsequent action may be reached.

8.5.3 Policy makers

We found that antigypsyism, i.e. ideas considering the capacities of segregated Roma partly low naturally (Albert et al. 2016), can adversely contribute to all the examined pathways leading to poor health status of the segregated Roma, including the apparently deliberate Roma nonadherence to clinical and public health recommendations (Figures 8.2-5). Moreover, this specific form of racism seems to be the fundamental cause driving CEE health inequalities between the Roma and the general populations. We also found that Roma health mediation programs, i.e. truly promising public health activities that target social determinants of health directly within segregated Roma enclaves (see Chapter 6), lack institutional stability and systematic state support. These findings imply that a more effective addressing of antigypsyism across governance levels and sectors could improve the outlook for better health of the segregated Roma in the region. This similarly entails a more systematic institutional support for community health work of the Roma health mediation kind. Making use of related current evidence-based recommendations within policy-making (Bailey et al. 2017; Came et al. 2018; Lehmann et al. 2007; Phillips 2011; WHO 2013b) might facilitate this route greatly.

More specifically, policymakers could start explicitly addressing antigypsyism as a fundamental driver of poor Roma health, e.g. by including related targets in the Action Plans of the National Roma Integration

Strategies (NRIS) within and beyond the area of health (cf. EUC 2018a; EUFRA 2018b). The generally poor understanding of racism and of current conditions and practices of segregated Roma could be addressed through increased provision of intelligible evidence-based explanations (EUFRA 2018b; Mullings 2005; Stewart 2013). This could e.g. occur as part of public education and via public media. Regarding health-mediation activities, state officials might consider full integration of positively evaluated programs into their national health systems (Farmer et al. 2013; Lehmann et al. 2007; Sándor et al. 2017). This would mean a much closer alignment of health mediation community-level activities with public health authorities' activities and the allocation of appropriate state funding for this.

8.5.4 Research

Our findings regarding Roma confirmed that adverse material circumstances, health-related behaviours, psychosocial pressures and healthcare use can contribute to the poor health of CEE segregated Roma. Further, we identified specific trade-off patterns in all such exposures (see Figures 8.3-4). And finally, we showed how these patterns were maintained by local structural conditions, including racialized ideologies of Roma natural incapacity, non-Roma discrimination of Roma and Roma socialization for ethnically framed countercultural norms (see Chapter 4). This implies that further research on exposure patterns and underlying mechanisms could use a similar approach as used in this thesis, i.e. structural-constructivist research paying close attention both to structural constraints and to how the people involved interpret these constraints (cf. Cockerham 2005; Elliott et al. 2015; Frohlich et al. 2001; Singer et al. 2016). This may help to elucidate the complex causal relationships outside the health systems that underlie the poor health of CEE Roma.

More specifically, future research on exposure patterns in CEE segregated Roma might benefit from consulting cross-cultural approaches to psychosocial pathways (Kirmayer 2006; Sanchez et al. 2006), e.g. to identify culture-bound stressors. Further, it might be fruitful for such research to consider the identified countercultural trade-off relationships between bonding and bridging social capitals (Carrasco et al. 2016; Moore et al. 2017). Similar trade-offs may also act via health literacy components (Batterham et al. 2016; Dodson et al. 2015; Greenhalgh 2015). Research on underlying mechanisms might benefit from considering racist ideologies and discrimination as causal pathways, including the related aspects of Roma socialization (Kendall et al. 2005; Siegal et al. 2005; Singer et al. 2016; Singh-Manoux et al. 2005).

Our findings regarding the health-system add evidence about the organisational features and societal influences that can drive the frequent ethnic discrimination of segregated Roma by healthcare frontliners, as well as the related roles of anti-Roma ideologies. We also showed that healthcare frontliners with a deeper understanding of segregated Roma conditions and practices can be more resilient towards these adverse influences. This implies that the qualitative “study up” approach used in this thesis indeed may help to elucidate drivers and pathways underlying adverse health-system contributions to the poor health of CEE Roma. In this approach, the drivers of ethnic discrimination are also explored by approaching the perpetrators of ethnic discrimination, not just its victims, as actors representing a specific culture. The approach thus pays also close attention to the culture-bound motivations and constraints of these perpetrators (Napier et al. 2014; Stich et al. 2015).

More specifically, future research on unequal care for segregated Roma might benefit from evidence on indirect forms of discrimination and racism within care systems (Ford et al. 2010b; Hicken et al. 2018; Lewis et al. 2015; Phillips 2011). Next, such research could also benefit from considering antigypsyism as a specific form of racism (Albert et al. 2016; EUFRA 2018b) (see Chapter 5 and Figure 8.5). Extending this research with a focus on the implicit clinicians’ biases towards the Roma may also be productive, given the significant findings that such an approach has yielded elsewhere (Hall et al. 2015; Maina et al. 2018; van Ryn et al. 2011). Our findings match with psychological theories on discrimination and inter-group contact (Kauff et al. 2017; Pettigrew 2016), implying that further research informed by these theories could yield more insights into how to curb the care discrimination against CEE Roma.

8.6 Conclusions

This thesis extends the understanding of the health inequalities between segregated Roma and the general populations in Central and Eastern Europe (CEE) with novel insights regarding three kinds of pathways: pathways between Roma practices and health outcomes within segregated Roma enclaves; pathways between health-system frontline services and segregated Roma affecting exposures of the Roma; and “upstream” determinants affecting both of the above pathways.

Regarding the first kind of pathways, the thesis adds that some CEE segregated Roma develop and socialize for ethnically framed racialized ideologies countercultural to local “non-Roma” standards of life, including

care. Such countercultural social norms work as trade-off mechanism that shape health-endangering exposures of individuals within the segregated enclaves in mixed ways, according to household social level.

Regarding the second kind of pathways, this thesis adds that frequent substandard healthcare towards segregated Roma can be sustained by a poor understanding of the conditions and practices of segregated Roma via related adverse organisational features. This can in turn lead to the Roma using healthcare services less effectively and to further exacerbation of specific health problems in the group.

Regarding the third kind of pathways, this thesis adds that both of the above pathways can be driven by a societal omnipresence of a specific form of racism targeting Roma: antigypsyism. This thesis also adds that the adverse influences of antigypsyism are mostly indirect and thus far not fully realized by everybody involved.

We therefore suggest that in order to better understand and tackle CEE inequalities concerning Roma, more focus is needed on the specific exposure pathways that we identified and on the fundamental underlying role of antigypsyism. We also suggest that a further use of ethnographic methods within such efforts is likely to be productive.

Summary

This thesis assessed the views and practices first of segregated Roma and then of health system professionals in Slovakia regarding the poor health status of segregated Roma in the country. It aimed to contribute to the understanding of the health inequalities between segregated Roma and the general populations in Central and Eastern Europe (CEE).

Roma, concentrated mostly in the CEE region, Turkey and Spain, present one of the largest and internally most variable ethnically defined populations in Europe. In their respective home countries, large proportions of CEE Roma reside in segregated enclaves, occupying the lowest societal positions and frequently experiencing harsh treatment. Although not comprehensive, published evidence convincingly indicates steep and persistent health inequalities between Roma and the general populations across the CEE region. CEE Roma have previously been shown to be more exposed to circumstances that are detrimental for health: poor material circumstances, high psychosocial pressure and more adverse health-related practices, including less effective use of healthcare services. Evidence regarding “upstream” determinants, i.e. circumstances determining the higher levels of exposures faced by segregated Roma, is much patchier and less conclusive. However, recent studies have indicated that discrimination of Roma and related social norms among segregated Roma may importantly contribute to the poor health of Roma.

We focused on health inequalities regarding segregated Roma in Slovakia, which are relatively well-studied and well exemplify the picture regarding Roma in CEE. More specifically, we identified and chose to address with our research the following three kinds of related evidence gaps: How do the health-endangering exposures that CEE segregated Roma face translate into their (poor) health? What makes large portions of CEE segregated Roma face these exposures? And, on what, why and how well do the health system interventions that try to improve the poor health of the Roma act?

We outline the thesis’s methodology in Chapter 2. Our research strategy was qualitative and explorative, i.e. observing and discussing practices and views of people personally involved in a poorly understood topic. We used mostly ethnographic methods, consisting primarily of techniques that enabled extensive data acquisition via detailed direct observations and in-depth interviews.

We carried out four empirical studies using three samples. For the first two studies, we obtained data from a single rural segregated Roma settlement with approximately 260 residents to assess the exposures,

health-related practices and supporting mechanisms within segregated Roma settlements in Slovakia. In the third study, we observed and interviewed a total of 43 healthcare professionals who met Roma on a frequent basis in six different healthcare facilities in five different geographical locations. We did so to assess Roma-related practices of healthcare professionals. For the fourth empirical study, we used a sample of over 70 staff members and 30 recipients of a national health-mediation program, in total covering over 200 segregated Roma localities in Slovakia. In all studies, our data consisted of written field notes on direct observations and informal elicitations, and of audio-recordings from structured interviews. In all studies, we coded and analysed the field notes and transcripts with respect to each of the studies' specific aims, using either conventional or directed qualitative content analyses.

Chapter 3 deals with our longitudinal study on health-endangering everyday settings and practices in a segregated rural Roma settlement. We found that for all the examined dimensions – material circumstances, psychosocial factors, health-related behaviours, social cohesion and healthcare utilization – the settlement's residents faced a wide range of health-endangering settings and practices. How the residents coped with these exposures and how these exposures affected the health of which residents varied according to local social stratifications. Material circumstances and perceived stressors varied the most, with the pattern of stressors partially deviating from that in the general population. Most identified patterns did not change over the decade in which the research took place, and the overall health gap from local non-Roma seemed to persist.

Chapter 4 covers our exploration of local-level mechanisms supporting segregated Roma nonadherence to clinical and public health recommendations. We identified seven such mechanisms: the Roma situation of poverty, segregation and substandard infrastructure; the value that Roma attribute to their alternative practices; exclusionary non-Roma and self-exclusionary Roma ideologies; discrimination, racism and dysfunctional support towards Roma by non-Roma; drawbacks of adherence; and Roma socialization into their situation. We found that these mechanisms formed an inter-locked system controlled by and operating through both local Roma and non-Roma.

Chapter 5 deals with the practices of healthcare frontliners regarding segregated Roma in Slovakia, the mechanisms supporting substandard practices, and the frontliners' resilience to such mechanisms. We found that the frontliners' substandard practices regarded mostly substandard communication and care commitment, but also overt ethnic discrimination. This outcome was supported by five mechanisms: frontliners' negative experiences with "problematic Roma patients"; frontliners'

negative attitudes regarding segregated Roma; adverse organizational aspects; adverse Roma-segregation aspects; and adverse societal-level influences. Over their careers, frontliners who started without negative attitudes towards segregated Roma patients first felt obliged and trying to provide adequate care. Thereafter they felt failing, unequipped and abandoned, and ultimately frustratingly resigned regarding equal standard of care.

Chapter 6 provides findings of our evaluation of how known social determinants of health (SDH) were addressed in the agenda and in the everyday implementation of a national health-mediation program (HMP) addressing segregated Roma communities in Slovakia. We found that in its agenda, the HMP addressed only health-related behaviours and healthcare access and set its goals regarding the latter in a way discouraging positive changes in the former. In the HMP's everyday implementation, activities that supported healthcare access appeared to be effective, well received by the HMP recipients and assistants and performed as set out by the latter. The opposite was true for most educational activities targeting health-related behaviours. The HMP fieldworkers were proactive and sometimes effective at addressing SDH domains beyond the HMP agenda. The HMP leaders supported such engagement only informally, finding the program inadequate and too unstable to handle any such extensions.

Based on some of the above findings and a literature review, in chapter 7 we share our response to the question of whether Roma and non-Roma patients need to be treated differently in clinical practice. We designed a step-by-step guideline for dealing with apparent clinical differences in Roma and non-Roma patient groups in clinical practice. The guideline recommends that clinical practitioners facing such differences start with assessing the significance and representativeness of the differences based on several criteria, then assess differences in relevant living conditions, and assess biological differences only if refuting the preceding.

In Chapter 8, we discuss all of the above and formulate overreaching findings and implications. In sum, we found that all examined mechanisms underlying the CEE Roma health gaps might be significantly shaped by racism explicitly targeting Roma, i.e. antigypsyism. Our findings and the available literature indicate that antigypsyism is very likely the fundamental cause driving these inequalities. We suggest that in order to better understand and tackle the inequalities, the identified effects of antigypsyism need to be studied and addressed more extensively.

More specifically, future research on exposure patterns of segregated Roma and underlying mechanisms could benefit from paying closer attention both to structural constraints of the Roma and how

they interpret these constraints. Future research on unequal practices in care and prevention regarding segregated Roma could benefit from paying closer attention to culture-bound motivations and constraints of the perpetrators of discrimination. CEE healthcare might become better for segregated Roma if healthcare managements would support their frontliners regarding skills and tools to understand and handle racism, the culture-bound and structural vulnerabilities of segregated Roma and their own professional expectations regarding health equity.

Public health initiatives addressing the poor health of the Roma might become more effective if they start approaching it as being an outcome of ethnic disparities in social determinants controlled by actors across societal levels and significantly affected by a general antigypsyism. Everybody involved might benefit if CEE policymakers would update the respective National Roma Integration Strategies, public education contents and media coverage based on recent evidence.

Samenvatting

Dit proefschrift gaat over de opvattingen en de dagelijks praktijk van gesegregeerde Roma en werkers in de zorg in Slowakije wat betreft de gezondheid van gesegregeerde Roma in Slowakije. Het proefschrift heeft als doel bij te dragen aan het begrip van de ongelijkheid in gezondheid tussen gesegregeerde Roma en de algemene bevolking in Centraal- en Oost-Europa (COE).

Roma, die voornamelijk wonen in COE, Turkije en Spanje, vormen één van de grootste en naar etniciteit meest heterogene bevolkingsgroepen in Europa. In hun respectievelijke thuislanden wonen de meeste COE-Roma in afgescheiden enclaves. Ze staan het laagst in maatschappelijke positie en worden vaak onvriendelijk behandeld. Hoewel beperkt, laten de weinige gepubliceerde gegevens overtuigend een sterke en voortdurende ongelijkheid in gezondheid zien tussen Roma en de algemene bevolking in de COE regio. Eerder is aangetoond dat COE-Roma meer blootgesteld zijn aan omstandigheden die schadelijk zijn voor de gezondheid: slechte materiële omstandigheden, hoge psychosociale druk en meer ongunstig gezondheidsgedrag, met ook een minder effectief gebruik van gezondheidszorg. Bewijs met betrekking tot “oorzaken van de oorzaken”, d.w.z. die omstandigheden die de hogere blootstellingsniveaus van gesegregeerde Roma bepalen, is veel meer fragmentarisch en minder overtuigend. Recente studies hebben echter laten zien dat discriminatie van Roma en de daarmee samenhangende normen van gesegregeerde Roma in belangrijke mate kunnen bijdragen aan de slechte gezondheid van Roma.

We hebben ons gericht op ongelijkheid in gezondheid van gesegregeerde Roma in Slowakije, die relatief goed bestudeerd zijn en een goed beeld geven van Roma in COE. Meer in het bijzonder kozen we ervoor om ons onderzoek te richten op de volgende drie soorten gerelateerde lacunes in kennis: Hoe leiden de gezondheidsbedreigingen waaraan de in COE wonende gesegregeerde Roma blootgesteld worden, tot hun (slechte) gezondheid? Wat maakt dat grote delen van COE gesegregeerde Roma met deze blootstelling wordt geconfronteerd? Tenslotte, waarop, waarom en hoe werken de gezondheidszorginterventies die de slechte gezondheid van de Roma proberen te verbeteren?

We schetsen de methodologie van het proefschrift in hoofdstuk 2. Onze onderzoeksstrategie was kwalitatief en exploratief, d.w.z. we observeren en bespreken praktijken en opvattingen van mensen die persoonlijk betrokken zijn bij een onderwerp dat we slecht begrijpen. We verzamelden onze gegevens voornamelijk met etnografische methoden, met name technieken die ons in staat stelden om systematisch gegevens te verzamelen via gedetailleerde directe observaties en diepte-interviews.

We hebben vier empirische onderzoeken uitgevoerd op basis van drie steekproeven. Voor de eerste twee onderzoeken verkregen we gegevens over één gesegregeerde Roma-nederzetting op het platteland met ongeveer 260 bewoners, om daarmee blootstellingen, gezondheidsgedrag en ondersteunende mechanismen binnen gesegregeerde Roma-nederzettingen in Slowakije te kunnen bepalen. In de derde studie hebben we in totaal 43 zorgprofessionals geobserveerd en geïnterviewd die regelmatig contact hebben met Roma in zes verschillende zorginstellingen op vijf verschillende geografische locaties. We deden dit om de Roma-gerelateerde praktijken van professionals in de gezondheidszorg te kunnen bepalen. Voor de vierde empirische studie gebruikten we een steekproef van meer dan 70 stafleden en 30 ontvangers van een nationaal programma voor gezondheidsbevordering, dat gericht is op in totaal meer dan 200 gesegregeerde Roma-gemeenschappen in Slowakije. In alle studies bestonden onze gegevens uit geschreven veldnotities over directe waarnemingen en informele gesprekken en uit geluidsoptnamen van gestructureerde interviews. In alle studies hebben we de veldnotities en transcripties gecodeerd en geanalyseerd wat betreft elk van de specifieke doelen van de studies, met gebruikmaking van zowel conventionele als gerichte kwalitatieve inhoudsanalyses.

Hoofdstuk 3 gaat over onze longitudinale studie naar gezondheidsbedreigingen binnen de alledaagse context en praktijken in een gesegregeerde Roma-nederzetting in landelijk gebied. We vonden dat voor alle onderzochte dimensies - materiële omstandigheden, psychosociale factoren, gezondheidsgerelateerd gedrag, sociale cohesie en het gebruik van gezondheidszorg - de bewoners van de nederzetting te maken hadden met een breed scala aan gezondheidsbedreigingen vanuit hun context en alledaagse praktijken. Hoe de bewoners handelden wat betreft deze blootstellingen en hoe deze blootstelling van invloed was op de hun gezondheid varieerde, mede afhankelijk van de lokale sociale stratificaties. Materiële omstandigheden en waargenomen stressoren varieerden het meest, waarbij het patroon van stressoren deels afweek van dat in de algemene bevolking. De meeste geïdentificeerde patronen veranderden niet gedurende de tien jaar dat we onderzoek deden en de algemene achterstand in gezondheid van Roma ten opzicht van lokale niet-Roma bleef bestaan.

Hoofdstuk 4 gaat dieper in op mechanismen op lokaal niveau die leiden tot het niet-volgen door Roma van klinische en preventieve aanbevelingen. We identificeerden zeven van dergelijke mechanismen: de positie van Roma met armoede, segregatie en een onvoldoende infrastructuur; de waarde die Roma hechten aan hun eigen benaderingen van gezondheid; ideologieën van niet-Roma die leiden tot uitsluiting en van Roma die leiden tot zelf-uitsluiting; discriminatie, racisme en

disfunctionele steun gericht op Roma door niet-Roma; nadelen van therapietrouw; en socialisatie en gewenning van Roma wat betreft hun situatie. We ontdekten dat deze mechanismen een in elkaar grijpend systeem vormen, dat wordt beheerst en blijft werken vanwege zowel lokale Roma als niet-Roma.

Hoofdstuk 5 gaat over de praktijken van zorgprofessionals met betrekking tot gesegregeerde Roma in Slowakije, over de mechanismen die ondermaatse zorgpraktijken ondersteunen en over de veerkracht van die professionals tegen dergelijke mechanismen. We vonden dat de ondermaatse zorg met name slechte communicatie en een geringe zorgbetrokkenheid betrof, maar daarnaast ook openlijke etnische discriminatie. Deze bevinding werd ondersteund door vijf mechanismen: negatieve ervaringen van professionals met “problematische Roma-patiënten”; een negatieve attitude van professionals wat betreft gesegregeerde Roma; nadelige organisatorische aspecten; nadelige aspecten van de segregatie van Roma; en ongunstige invloeden op het niveau van de gehele maatschappij. In hun loopbaan voelden professionals die zonder negatieve houding ten opzichte van gesegregeerde Roma-patiënten waren begonnen zich eerst verplicht om gelijkwaardige zorg te realiseren en spanden zich daarvoor in. Daarna voelden ze zich tekortschietend, niet uitgerust en in de steek gelaten, en haakten uiteindelijk gefrustreerd af in het leveren van zorg van voldoende niveau.

In Hoofdstuk 6 gaan we in op onze evaluatie van hoe bekende sociale determinanten van gezondheid (SDG) werden aangepakt in de opzet en implementatie in de praktijk van een nationaal programma voor gezondheidsbevordering, dat is gericht op gesegregeerde Roma gemeenschappen in Slowakije. We ontdekten dat dit programma in haar opzet alleen is gericht op gezondheidsgedrag en toegang tot gezondheidszorg en dat de doelen met betrekking tot het laatste zo zijn geformuleerd dat positieve veranderingen worden ontmoedigd. In de dagelijkse implementatie van dit gezondheidsbevorderingsprogramma leken activiteiten die de toegang tot de zorg ondersteunen effectief te zijn, goed te worden ontvangen door de doelgroep en de uitvoerders van het programma en te worden uitgevoerd zoals bedoeld. Het tegenovergestelde gold voor de meeste voorlichtingsactiviteiten gericht op het veranderen van gezondheidsgedrag. De veldwerkers van het HMP waren proactief en soms effectief in het aanspreken van SDG-domeinen buiten de formele agenda van het programma om. De leidinggevenden van dit programma ondersteunden een dergelijke betrokkenheid alleen informeel en vonden het programma ontoereikend en te instabiel om met dergelijke uitbreidingen om te gaan.

Op basis van de bovenstaande bevindingen en een literatuuroverzicht gaan we in hoofdstuk 7 in op de vraag of Roma- en niet-Roma-patiënten

in de klinische praktijk anders behandeld moeten worden. We ontwikkelden een richtlijn voor het omgaan met zichtbare klinische verschillen tussen Roma- en niet-Roma-patiëntengroepen in de klinische praktijk. De richtlijn beveelt aan dat klinische behandelaars die met dergelijke verschillen worden geconfronteerd, beginnen met het beoordelen van het belang en de representativiteit van deze verschillen op basis van een aantal criteria, vervolgens de verschillen in relevante leefomstandigheden beoordelen, en biologische verschillen alleen mee nemen als al het voorgaande niet van toepassing blijkt.

In hoofdstuk 8 bespreken we de verschillende bevindingen en formuleren overkoepelende bevindingen en implicaties. Samenvattend vonden we dat alle onderzochte mechanismen die ten grondslag liggen aan de achterstand in gezondheid van COE-Roma mogelijk in belangrijke mate gevormd wordt door racisme dat expliciet gericht is tegen Roma, d.w.z. antigypsy-isme. Onze bevindingen en de beschikbare literatuur geven aan dat het antigypsy-isme zeer waarschijnlijk de fundamentele oorzaak is van die ongelijkheid. We stellen voor dat om die ongelijkheid beter te begrijpen en aan te pakken, deze effecten van antigypsy-isme verder moeten worden bestudeerd en fors moeten worden aangepakt.

Meer specifiek zou toekomstig onderzoek naar blootstellingspatronen van gesegregeerde Roma en naar de onderliggende mechanismen baat kunnen hebben bij meer aandacht voor zowel de structurele beperkingen van de Roma als voor de manier waarop zij omgaan met deze beperkingen en deze interpreteren. Toekomstig onderzoek naar verschillen in zorg en preventie wat betreft gesegregeerde Roma zou baat kunnen hebben bij meer aandacht voor de cultuurgebonden motieven en beperkingen van degenen die Roma discrimineren. De gezondheidszorg in COE kan beter worden voor gesegregeerde Roma als zorginstellingen hun professionals ondersteunen wat betreft vaardigheden en middelen die hen helpen in het beter begrijpen van racisme, de cultuurgebonden en structurele kwetsbaarheden van gesegregeerde Roma en hun eigen professionele verwachtingen wat betreft gelijkheid in gezondheid.

Public health initiatieven die zijn gericht op de slechtere gezondheid van Roma, kunnen effectiever worden als ze deze achterstand benaderen als zijnde het resultaat van etnische ongelijkheden in sociale determinanten, die op hun beurt worden in stand gehouden door maatschappelijke en bestuurlijke factoren en die in aanzienlijke mate worden beïnvloed door een algemeen antigypsy-isme. Alle betrokkenen kunnen er baat bij hebben als bestuurders in COE hun nationale beleid voor Roma-integratie actualiseren op basis van recente kennis, en eveneens de inhoud van de publieksvoorlichting en de berichtgeving in de media.

Zhrnutie

Táto práca pojednáva o tom, čo a prečo si na Slovensku ohľadne zdravia vylúčených Rómov myslia a čo ohľadne neho bežne robia jednak títo Rómovia samotní, a jednak rôzni profesionáli zdravotného systému. Jej zámerom bolo prispieť k pochopeniu príčin nerovností v zdravotnom stave medzi Rómami a ne-Rómami v Strednej a východnej Európe (SVE).

Rómovia, koncentrovaní najmä v SVE, Turecku a Španielsku, tvoria jednu z najpočetnejších a najrozmanitejších etnicky vymedzených populácií v Európe. Značná časť Rómov v krajinách SVE pritom predstavuje ľudí s najnižším možným spoločenským postavením, obývajúcich vylúčené osídlenia a čeliacich mimoriadne príkrým prístupom od ostatných ľudí. Hoci tematicky stále deravý, dosiaľ publikovaný vedecký výskum presvedčivo ukazuje, že medzi týmito Rómami a ostatnými populáciami pretrvávajú naprieč celým regiónom veľké nerovnosti aj v zdravotnom stave. Pokiaľ ide o bezprostredné príčiny posledného uvedeného, za rovnako presvedčivo preukázanú možno považovať i všeobecne rozšírenú predstavu, že vylúčenie Rómovia v SVE sú jednoducho nadmerne vystavení množstvu okolností, ktoré sú pre zdravie škodlivé: biednym materiálnym podmienkam, vysokej psychosociálnej záťaži, rizikovému správaniu súvisiacemu so zdravím a málo efektívnemu využívaniu služieb zdravotnej starostlivosti. Pokiaľ však ide o vedecké dôkazy ohľadne determinantov zdravia pôsobiacich takpovediac vyššie proti prúdu, t.j. ohľadne okolností, ktoré zapríčiňujú to, že zdravie-ohrozujúcim okolnostiam sú častejšie a viac vystavení práve vylúčenie Rómovia, celkový obraz je zatiaľ o dosť nejasnejší. Až nedávne vedecké štúdie začali ako potenciálne dôležité determinanty potvrdzovať diskrimináciu a súvisiace sociálne normy i na pomyselnéj rómskej strane.

My sme sa v našej práci zamerali na nerovnosti v zdravotnom stave medzi vylúčenými Rómami a bežnou populáciou na Slovensku, kde je tento druh nerovností výnimočne dobre preukázaný, a kde sa doterajšie zistenia zdajú dobre ilustrovať aj situáciu inde v SVE. Presnejšie, pokúsili sme sa priniesť nové poznatky k trom druhom otázok, ktoré boli ohľadne týchto nerovností aj na Slovensku dovtedy prebádané najmenej: Ako presne konkrétne zdravie-ohrozujúce okolnosti vo vylúčených rómskych osídleniach spôsobujú horší zdravotný stav tamojších obyvateľov? Prečo sú takýmto zdravie-ohrozujúcim okolnostiam vystavené značné časti práve rómskej populácie? A napokon, na základe čoho, prečo tak, a s akým úspechom sa tento stav pokúša riešiť miestny zdravotný systém?

V Kapitole 2 zhrňame, ako sme postupovali. Naša výskumná stratégia spočívala v tzv. kvalitatívnej explorácii: dosiaľ slabo prebádanú oblasť praxe sme preskúmavali prostredníctvom pozorovaní a diskusií

každodenných zvyklostí a pohľadov ľudí v nej zainteresovaných. Na vytvorenie samotných dát o preskúmanom sme používali predovšetkým etnografické nástroje, teda nástroje pozostávajúce z postupov umožňujúcich dlhodobéjšie získavanie a zaznamenávanie podrobných zúčastnených pozorovaní a rozhovorov.

Na troch výskumných vzorkách sme uskutočnili dovedna štyri empirické štúdie. V prvých dvoch štúdiách sme sa zamerali na zdravie-ohrozujúce okolnosti charakteristické pre súčasné vylúčené rómske osídlenia na Slovensku, resp. na ich zloženie, pôsobenie, a na mechanizmy, ktoré tieto okolnosti udržiavajú v dlhodobom horizonte. Dáta pre obe tieto štúdie sme nadobudli v rámci dlhodobého etnografického pobytu v segregovanej vidieckej rómskej osade na južnom Slovensku s počtom obyvateľov približne 250. V tretej štúdii, zameranej na pohľady a každodenné zvyklosti profesionálov systému zdravotnej starostlivosti, ktorí pracujú s vylúčenými Rómami na dennej báze, sme v piatich geografických lokalitách a šiestich zdravotníckych zariadeniach postupne pozorovali a spýtovali celkovo 43 takýchto profesionálov rôznych profesií a riadiacich úrovní. V štvrtej štúdii, kriticky preskúmajúcej zámery a každodennú prax národného intervenčného programu pôsobiaceho vo vyše 200 vylúčených rómskych osídleniach naprieč Slovenskom, sme pozorovali a spýtovali viac ako 70 zamestnancov a 30 prijímateľov tohto programu. Samotné dáta nadobudnuté vo všetkých uvedených štúdiách pozostávali jednak z podrobných rozsiahlych poznámok o priamych pozorovaniach a neformálnych rozhovoroch, a jednak zo zvukových záznamov z rozhovorov štruktúrovaných a hĺbkových. Všetky tieto dáta sme zakaždým kodovali a analyzovali podľa daných špecifických výskumných cieľov, a to za použitia buď konvenčnej alebo tzv. orientovanej kvalitatívnej obsahovej analýzy.

V Kapitole 3 pojednávame o zdravie-ohrozujúcich okolnostiach a každodenných zvyklostiach priamo v jednej z vylúčených rómskych osád v priebehu desiatich rokov. Obyvatelia tejto osady boli trvalo vystavení širokej škále zdravie-ohrozujúcich okolností a zvyklostí naprieč všetkými skúmanými doménami, zahŕňajúcimi materiálne podmienky, psychosociálnu záťaž, správanie súvisiace so zdravím, sociálnu súdržnosť a starostlivosť o zdravie. Zistili sme, že to, ako presne boli ktorí obyvatelia vystavení a zapojení do konkrétnych podmienok, sa v rámci osady líšilo najmä podľa príslušnosti ich domácnosti k miestnym spoločenským vrstvám. Materiálne podmienky a psychosociálna záťaž sa v rámci osady líšili najviac, pričom druhá skupina zahŕňala niekoľko neobvyklých stresorov a chýbalo v nej niekoľko stresorov bežných inde. Väčšina zistených podmienok a zvyklostí sa za dekádu výskumu takmer nezmenila a celkové nerovnosti v zdravotnom stave pri porovnaní s miestnymi ne-Rómami tu takisto pretrvali.

V Kapitole 4 sa venujeme mechanizmu, ktoré v dlhodobom horizonte udržiavali zdravie-ohrozujúce okolnosti a zvyklosti zaznamenané v danej osade v predošlej štúdii. Takýchto mechanizmov sme určili sedem: rómsku situáciu vylúčenia, chýbajúcu infraštruktúru a chudobu; rómske prikladanie hodnoty zvyklostiam alternatívnym k nerómskym; seba-vylučovacie rómske a vylučujúce nerómske ideológie; diskrimináciu, rasizmus a dysfunkčnú podporu zo strany ne-Rómov; relatívne nevýhody dodržiavania medicínskych odporúčaní; a rómsku socializáciu na danú situáciu. Viaceré z týchto mechanizmov boli kontrolované skôr miestnymi ne-Rómami a všetky spoločne tvorili systém, v ktorom sa vzájomne podporovali.

V Kapitole 5 zaostrujeme na pohľady a každodenné zvyklosti radových pracovníkov zdravotníctva ohľadne vylúčených Rómov, mechanizmy, ktoré u týchto profesionálov podporujú podštandardné praktiky, a odolnosťou týchto profesionálov proti takýmto mechanizmom. Zistili sme, že podštandardné praktiky zdravotníkov vo vzťahu k vylúčeným Rómom zahŕňali predovšetkým horšiu komunikáciu a zníženú dôslednosť, no zaznamenali sme i otvorenú etnickú diskrimináciu. Takáto prax bola podporovaná piatimi mechanizmami: negatívnymi skúsenosťami zdravotníkov s „problematickými rómskymi pacientmi“; negatívnymi postojmi zdravotníkov ohľadne Rómov; neprimeranou organizáciou prevádzok; situáciou vylúčenia, chýbajúcej infraštruktúry a chudoby na strane vylúčených Rómov; a viacerými nepriaznivými celospoločenskými normami. Mnoho radových zdravotníkov svoje kariéry započalo bez negatívnych postojov k Rómom, cítiac sprvoti naopak silný záväzok pomáhať bez výnimiek. I v takýchto prípadoch však typicky nasledovali vo vzťahu k vylúčeným Rómom značné neúspechy, pocity nedostatočnej vybavenosti až ponechanosti napospas neriešiteľnej situácii, a napokon frustrovaná rezignácia na nediskriminujúci prístup.

V Kapitole 6 zhŕňame naše systematické zhodnotenie toho, ako sa so známymi sociálnymi determinantmi zdravia (SDZ) vo svojej vytýčenej agende a vo svojej každodennej praxi pasoval národný zdravotne-mediacný program (ZMP) zameraný na vylúčené rómske osídlenia. Zistili sme, že pokiaľ išlo o agendu, daný ZMP si kládol úlohy zamerané výhradne na vedomosti a zvyklosti Rómov súvisiace so zdravím a na bariéry v dostupnosti zdravotnej starostlivosti pre Rómov, oboje navyše spôsobmi, ktoré sa vzájomne podkopávali. Čo sa týka samotnej praxe, aktivity programu, ktoré sa zameriavali na bariéry v prístupe k starostlivosti sa javili ako vykonávané podľa plánu, dobre prijímané ľuďmi z cieľovej populácie a efektívne. Pre aktivity zamerané na zvyšovanie vedomostí a zmeny správania súvisiaceho so zdravím platil opak. Terénni pracovníci ZMP však zároveň boli značne proaktívni a často i úspešní aj ohľadne ďalších SDZ nad rámec agendy programu. Vedenie ZMP tento druh nadpráce síce

bežne podporovalo, no len neformálne, pretože program považovalo za inštitucionálne príliš ohrozený na to, aby mohol ašpirovať na podobné rozšírenia záberu.

Vychádzajúc z viacerých zistení uvedených vyššie a zo súvisiacej odbornej literatúry, v Kapitole 7 ponúkame našu odpoveď na otázku, či a v čom by sa zdravotná starostlivosť mala líšiť vo vzťahu ku ktorým rómskym a nerómskym pacientom. Pre klinických pracovníkov, ktorí majú dojem existencie podstatných rozdielov medzi rómskymi a nerómskymi pacientmi sme sformulovali odpoveď na to, ako sa s ním zodpovedne vysporiadať, v podobe stručného praktického návodu. Náš návod zhŕňa prečo a ako presne je v takýchto prípadoch potrebné postupovať od preskúmania štatistickej významnosti a reprezentatívnosti daných rozdielov cez vyjasnenie a legitimáciu vlastných kritérií určovania etnicity pacientov ku stanoveniu veľkosti rozdielov v životných podmienkach pacientov, ktoré s danými rozdielmi môžu súvisieť – pokusy o stanovovanie biologických rozdielov sú na mieste až v prípade, že ich prípadnú potrebnosť v danom konkrétnom prípade potvrdia predchádzajúce kroky.

V Kapitole 8 otvárame širšiu diskusiu o všetkých uvedených zisteniach, formulujeme zistenia presahujúce, a zhŕňame, čo by podľa nás z ktorých z nich malo z akých dôvodov pre koho vyplývať. Azda našim najdôležitejším presahujúcim zistením je, že bez výnimky všetky úrovne príčinnno-následných vzťahov, ktoré sme preskúmavali, boli významne negatívne ovplyvňované špecifickým druhom rasizmu, útočiacim vyslovene na Rómov, tzv. anticiganizmom. Toto naše a súvisiace predošlé zistenia totiž naznačujú aj to, že práve anticiganizmus veľmi pravdepodobne predstavuje samotnú fundamentálnu príčinu nerovností v zdravotnom stave medzi Rómami a ne-Rómami v regióne. Na lepšie pochopenie a efektívnejšie odstraňovanie týchto nerovností by teda bolo vhodné sa viac zamerať práve na anticiganizmus aj v ďalšom výskume, resp. v intervenčnej praxi.

Súdiac podľa našich zistení, budúci výskum toho, ako presne a prečo býva zdravie vylúčených Rómov v regióne poškodzované v tak nadštandardnej miere, by každopádne mohol mnoho získať dôslednejším dvojitém zameraním sa jednak na štrukturálne obmedzenia, ktorým daní vylúčení Rómovia čelia, a jednak na to, ako daní Rómovia tieto obmedzenia sami chápú. Podobne, budúcemu výskumu príčin častej podštandardnej zdravotnej starostlivosti vo vzťahu k vylúčeným Rómom by mohlo prospieť zameranie sa na štrukturálne a kultúrne podmienené motivácie a obmedzenia diskriminujúcich zdravotníkov. Samotná zdravotná starostlivosť vo vzťahu k vylúčeným Rómom by sa mohla stať férovejšou, keby manažmenty zdravotníckych zariadení začali svojich radových pracovníkov podporovať v zručnostiach a vybavení potrebných na zvládanie pestrých podôb anticiganizmu a jeho dôsledkov, štrukturálne

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About the author



Andrej Belak (1979) happens to come from Slovakia. He left his studies in philosophy (University of Vienna and Charles University in Prague) for natural science, eventually earning an MSc in human biology (Department of Anthropology and Human Genetics, Charles University). Having along the way performed extensive ethnographic research focusing on health-related practices and perspectives within a segregated Roma settlement in Slovakia (2004-2014), his focus has, however, remained rather humanistic. With his follow-up qualitative

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