Roma Health Mediators: A Neocolonial Tool for the Reinforcement of Epistemic Violence?

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Abstract

Scientific articles in medical journals regarding Roma have produced a type of problematic consensus narrative that is reinforced through its formulaic repetition. Roma health mediator (RHM) programs seem to have evolved from and currently be part of this consensus narrative. In this article I examine the potential use of RHMs, even if unintended, as a neocolonial tool for the reinforcement of epistemic violence against Roma, using a critical analysis of four empirical stories from the field. I explore the above hypothesis through critical reflexive anthropology, and postcolonial and intersectional studies, as well as by using elements of the self-ethnographic approach. I argue that the epistemic violence can be seen as resulting from the interplay between the Subject (i.e., health professional or researcher), the Object (i.e., Roma as "Other"), and the practices that result (i.e., discourse or consensus narrative production through the interpretation of the scientific data). I conclude with tools that could help reduce the epistemic violence against Roma within the health sector, such as cross-disciplinary collaboration, participatory action research (PAR), (self-)reflection, critical theory, and the dialogic creation of scientific knowledge.

Keywords

- Roma health mediators
- Reflexive anthropology
- Critical and postcolonial theory
- Epistemic violence
- Governmentality

Introduction

> *Roma are among the socially vulnerable population groups that have suffered many years of discrimination. This has resulted in isolation, poverty, and social exclusion from goods such as education, health, work, and housing. In addition, despite all the programs that have been implemented and the policies that have been applied, the situation is not improving.*

The above paragraph, variations of which I have used several times in my writings (Petraki 2014a; 2014b), could, according to Surdu (2016, 188), be the image of Roma resulting from the aggregation of scientific and expert practices, which aligns as well with the more general societal expectations for categorization. More specifically, this paragraph could be an example of what Kühlbrandt (2017, 17–18), who draws on Surdu, considers a brief "consensus narrative," found in the introductory part of articles regarding the health of Roma, published in scientific journals.

This consensus narrative is reinforced through the formulaic repetition of basic concepts that abound in the academic literature regarding Roma: a large and distinct population size, general poverty and social exclusion, a sense of identity, strong traditions and history, the political inadequacy of addressing their inequalities, suffering from discrimination, suffering from poor health, and so on (*ibid*., 17–18). However, as Kühlbrandt argues (*ibid*., 27–8), the absence of critical engagement, the process of knowledge production, and the politics of knowledge about Roma health within this consensus narrative are very problematic.

In this paper, I focus on Roma health mediators (RHMs),[1] who are considered to be a bridge between Roma communities, health personnel, and local authorities, and whose aim is to improve access to health care for Roma. More specifically, I explore the possibility that they may be used as a neocolonial tool in the hands of health professionals and researchers who might reinforce, even if unintentionally, the epistemic violence produced through the consensus narrative or discourse regarding Roma health.

In the first section, I briefly refer to the epistemic violence, as an act of interpreting scientific data by problematizing the Other, and the problematic consensus narrative regarding Roma that has been produced by the health sector. Also, I explain the way that RHMs may have become a part of a mechanism for epistemic violence against Roma. In the second section, I provide and comment on four relevant empirical anecdotes from the field. More specifically, based on the work of critical scholars, I examine the roles that can be attributed to the RHMs within the long-established public health research context, their "use" as valuable tools within the process of reinforcing the Roma problematic consensus narrative, and the way they can be seen by their communities. Finally, based on remarks in these anecdotes, I suggest a mechanism for countering epistemic violence against Roma in the field of health.

1 Due to a word limit, I chose to omit the general historical and conceptual background of mediation in Romani communities, as well as their successes and challenges. For those who would like to gain more information, please refer to the educational program "Young Roma Health Mediators Trainers and Presenters' Manual" (Petraki 2014a).

1. Positionality in the Field

As a brief disclosure of my positionality in the field, my first collaboration with Roma cultural mediators was in 2011, as a coordinator of the "Health promotion of Roma children" component within an EU operational program, run by the Centre for Intercultural Education at the National and Kapodistrian University of Athens (NKUA). Almost two years later, through my participation at a one-year training program of the Council of Europe (CoE), I designed the first pilot program for RHMs in Greece. The program was completed successfully in 2014 with the support of the nongovernmental organization (NGO) PRAKSIS and the contribution of several volunteers. The following two years, I continued collaborating with Roma cultural and health mediators within the first national health examination survey of Greece, "Hprolipsis," run by the Medical School of Athens.

A couple of years later, as a PhD student focusing on the health of Romani populations, as well as a master's student of social and cultural anthropology, I felt the need to revert to my past experiences regarding cultural and health mediation in Romani communities. The aim was to review my previously "established" perceptions on that subject in the light of social anthropology and reflexive ethnography, whereby the ethnographer becomes part of the inquiry. Would I approach Romani communities in a different way as a postgraduate student of social anthropology? Would I change the way I had designed and implemented the programs I took part in? To what extent had I realized at that time the power of my identity as a young, white, non-Romani and educated woman with links to university institutions, hospitals, and NGOs? Was there a chance that I, as a health professional and researcher who had been involved in Romani public health projects, had produced epistemic violence?

Having come from the field of health sciences, including nutrition, public health, international medicine, health crisis management, and epidemiology, and having absolutely no relation with social sciences, the majority of Romani literature that I had studied in the past could not help me in finding the answers to the above questions. On the contrary, it seemed it had masked rather than challenged any motive for reflection. My critical thinking was leaning on quantitative studies, biochemical and biological processes, economic theories, program evaluations, and strictly structured texts written in passive voice.

Most of the relevant literature I had read in the past were mainly produced by state bodies (e.g., the Hellenic General Secretariat for Population Education, USAID), European Union bodies (e.g., the European Commission, the European Centre for Disease Prevention and Control), United Nations agencies (e.g., the United Nations Development Program, UNICEF, the World Health Organization), international organizations (e.g., the CoE), charity organizations (e.g., Open Society Foundations), and NGOs (e.g., Romani CRISS, Fundación Secretariado Gitano). These publications had provided me with quantitative results about the health status of Roma, possible correlations between the health of Roma and causal socio-political factors, Roma health policy reports, and reports about the successes and the challenges of Roma health mediation programs.

However, when I started searching the literature by adding the keyword "ethnography," I began to discover what to me was a new field, one of reflection and critical theory in the science of anthropology.

Thus, I began to identify a new wave of critical approaches to the narratives concerning Roma, as expressed through the work of Charlotte Kühlbrandt (2017), Angéla Kóczé (2011), Huub van Baar (2011), Joanna Kostka (2015a; 2015b), Adina Schneeweis (2009; 2013; 2015), Mihai Surdu (2016), Nidhi Trehan (2001; 2009), and others, most of whom also referred to theories of postcolonialism (e.g., Foucault 1972; 1973; Spivak 1988, Said 1993; Spivak 1999) and intersectionality (e.g., Davis 1981; Abu-Lughod 1991; 1998).

This new wave of critical scholars worked in several areas, scrutinizing the political shift towards Roma after the fall of communism and the rendering of Roma as a "problem" and as "the largest minority in Europe" (van Baar 2011; Vermeersch and van Baar 2017); the deeply rooted scientific practices that have made an ethnic group a measurable and objectifiable entity through the process of essentialization, the narratives that homogenize them, and the role that the media play in reinforcing stereotypes (Schneeweis 2009; Surdu and Kovats 2015; Surdu 2016; Kühlbrandt 2017); the need for intersectional analysis, such as the limited references to the social struggle of Romani women and to the narrative used by NGOs to promote their rights and empowerment (Kóczé 2011); and the neoliberal policy that lay behind developmental programs and integration policies, and the neocolonialism of the hegemony of academic disciplines and foundations (Trehan 2009; Trehan and Kóczé 2009; Kóczé 2011; Kostka 2015a; 2015b).

Through my engagement with these scholars, I began to focus on their critical approach, which, to a certain extent, captured my own perception of the "Roma issue" – a perception I had yet to articulate. At that time, I realized that I would have to revisit the assumptions – personal, political, academic, and professional – that informed my approach to Roma and especially to Roma mediators.

Methodology

For the purpose of this article, I chose to focus on critical reflexive anthropology, postcolonial studies, and interdisciplinary studies. This approach would help me to critically examine the cultural identity attributed to Roma through the exploration of political, social, and economic issues that focus on oppression, conflict, struggle, power, and practice (Schwandt 1997, 22; Marcus and Fischer 2016). Moreover, elements of the self-ethnographic approach would allow me to highlight the personal shift in my critical perception regarding Roma health promotion and RHMs. At the same time these elements would help me avoid thinking in deeply rooted binaries, such as researcher and researched, objectivity and subjectivity, self and others (Ellingson and Ellis 2008, 450–9; Méndez 2013, 281; Adams 2015, 1–2).

Through using these approaches, I could offer critical reflection (Kennedy and Mayhew 2004) not as a distant researcher but as a person who had trained RHMs and collaborated with them for more than five years. Also, I could further contribute to lessening the gap in the literature on how mediation works in practice (Kühlbrandt 2017, 44).

The data I used, consisting of four short empirical stories from the field, come from notes I kept in my personal diary and video footage that was produced while I was involved in the "Young Roma Health Mediators" and "Hprolipsis" programs. These stories were selected based on the relevance of their content to the aim of this article, as explained above. The main people in these stories are aware of and agree with the use of this material.

2. The Production of Epistemic Violence through the Roma Health Discourse/Consensus Narrative

Spivak, in her famous essay "Can the Subaltern Speak" (1988), was the first to develop the term "epistemic violence," which refers to the colonial knowledge practices that have been applied in "third world" countries. More specifically, Spivak uses the term "epistemic violence" in regard to the discourses of knowledge that have been produced by various projects in literature, history, and culture, through which the colonial subjects have been constituted as "Other."

The health sector plays an important role regarding the epistemic violence that has been practiced and continues to be practiced towards Roma, as a governmentality field that includes a wide range of control techniques, such as biopolitics (Foucault 2008, 317). The following are a few examples from this field: its central role regarding the biopolitical methods of eugenics and techniques of population control, for instance the sterilization of Romani women without their consent (Zampas and Lamačková 2011; Albert and Szilvasi 2017); attributing responsibility regarding health status to Romani cultural characteristics, thus perceiving culture as static and ignoring at the same time the social, political, and economic dimensions associated with this issue (e.g., Roman et al. 2013, 850; Bobakova et al. 2015; Council of Europe 2016, 46); the linking of Roma with the concepts of risk and threat through the emphasis in the literature on communicable diseases and Roma – an emphasis that tends to reflect a concern for the needs of the general population rather than for the needs of Roma (Hajioff and McKee 2000, 868); the projection of Roma as a "problem," which necessitates targeted intervention (Matras 2015, 30); and the production of knowledge through studies that contribute to the homogenization and reinforcement of stereotypes under the umbrella term "Roma," often not taking into account differences in nationality, social class, educational level, and living conditions (Surdu and Kovats 2015; Surdu 2016, 250; for examples of the above approaches, see Kalaydjieva, Gresham, and Calafell 2001; Zeman, Depken, and Senchina 2003; and Vivian and Dundes 2004).

Kühlbrandt developed the term "consensus narrative" (2017, 17) in relation to the Romani narrative produced through the health sector in particular, as has already been mentioned in the introduction. According to Kühlbrandt, given the limitation in the number of words in many academic journals, authors have limited space to refer to the environment, background, and modern complexities of their subject matter, prior to focusing on their research questions. As a result, they end up using common descriptions – not just in the health sector but also in other disciplines such as education, housing, and work. Moreover, not only is this narrative reproduced in scientific journals, it is similar to that used in Roma policymaking (e.g., in World Bank reports), with the same language and stories being used. Academic and policy literature cross-reference each other, and as a result this consensus narrative is further entrenched.

Furthermore, Kühlbrandt (2017, 29–30) argues that RHMs programs have evolved from and are currently part of this consensus narrative. For example, according to van Baar (2018, 7), the narrative regarding metaphors of gaps, traps, vicious circles, and bridges has become an integral

part of the developmental discourses of international governmental organizations. This has led to the institutionalization of bridging "mediators" in the domains of healthcare, schooling, policing, and community or labour-market interventions. This in turn was epitomized by the 2011 EU/CoE-funded ROMED[2] initiative.

In addition, over the last few years, more and more critical scholars have problematized the institution of Roma mediators. More specifically, Kóczé (2019, 202), commenting on the ROMED project, argues that even though it aims to empower Romani community members and create inclusive public institutions, the program's design, ideology, and rationale are based on prevalent discourses about Roma as "underdeveloped" and culturally "Other." Thus, it failed to highlight the deep structural, socio-racial, and spatial inequalities. Also, the framing of the program in terms of individual communication and behavioural matters seems to ignore power relations and required structural changes (*ibid*., 197).

Moreover, according to Clark, within health promotion as well as in improving access to educational opportunities, the "gains" acknowledged by Roma mediators through their work:

> are illustrative of a *gadzhe* "social inclusion" model that still views Roma communities as largely dependent and lacking in both agency and ability to articulate need and represent collective, democratic thinking and governance. This is a redundant, neocolonial model in the 21st Century and one that needs to be stripped of power, control and influence (2018, 195–6).

The concept of epistemological violence in empirical social sciences, according to Teo (2010), has a Subject, which is the researcher, an Object, which is the Other, and an action, which is the interpretation of data that is presented as knowledge. Borrowing this idea and focusing on the public health sciences, I will argue that the epistemic violence against Roma comes out of the long-established interplay between the Subjects, which are the health professionals and researchers; the Object, which is Roma as "Other", and the ensuing practices, which produce the discourse/consensus narrative through the interpretation of the scientific data. Also, I will try to show that in recent years, RHMs may have been used as a new neocolonial tool for the reinforcement of epistemic violence against Roma by the Subjects, that is, health professionals and researchers, along with the scientific practices they have already been using, such as counting, classifying, mapping, sampling, predicting, photographing, and DNA profiling (Surdu 2016, 247. For a depiction of this mechanism, see Figure 1).

2 The European Training Programme for Roma Mediators (ROMED) aims to reinforce mediators' skills to facilitate communication and cooperation between Roma and public institutions, especially schools, health services, and employment offices. For more information, see http://coe-romed.org.

3. Empirical Case Studies

'Young Roma Health Mediators'

The training course "Young Roma Health Mediators" was implemented in Greece in 2014 by PRAKSIS and was cofunded by the European Youth Foundation. The aim of this pilot project was to raise awareness concerning the fundamental human right to medical care in selected Romani settlements of the Attica region, by improving health literacy. One of the main objectives of the program was to train 20 young Roma from the Attica region as mediators on health issues (for more information on the project, see Petraki 2014a).

Below, I provide and comment on two anecdotes. The first is an excerpt from video footage taken during the theoretical part of the training course. The second, notes of which were kept in my diary, took place about one year after the end of the project.

What Is a Mediator?

The following discussion took place during the training module "What Is the Role of the Mediator?" Roma trainees were asked to share their opinion on this question.

> Trainee A: I believe a mediator is the human link that will mediate for a community of people who are weak.
> Trainer: Nice. Let's go, next one.
> Trainee B: What I have understood is that it is the bridge between logic and absurdity, for people who are illiterate, have anger, are abusing drugs, are sick and do not have the courage to reclaim and process things. I believe that I will be a model, a peculiarity for my race. I have made a picture in my mind that all these social actors who are shutting the door to us, either because my race is to blame or because we did not move forward, will allow me in… I can be the link that connects people with needs, but not someone who goes wherever he wants. It's not possible to be an employee and suddenly to go to the manager; there has to be a path, and that, I think, we are going to learn through experiences, such as the ones you have. You should have well-established arguments, you have to claim, not to demand… just like my mother says, "The sleep you will get depends on the way you will make your bed."
> Trainee C: I believe that the mediator's role is for some people who do not have knowledge, for people that cannot follow some other people… we will go and open the doors to mediate and do what we have to do.
> Trainee D: Provide information on rights and what we have to get. In addition to this, mediators, and especially young people, can exchange opinions among us and give solutions. I would say that we are a software in society that can bring a proper outcome to problems and racism… to be able to fight racism and thus to move forward, to have a better life and to evolve.

Schneeweis (2015, 88), using concepts from Foucault (1973) and Lefebvre (1991), argues that "perceptions of the mediators' power roles change between institutional landscapes (spaces of hegemonic directives),

Romani communities (conceived space where the women have symbolic control), and the lived space of resistance and internalized discrimination." In the above dialogue, the distinction between these three different spaces appears once again, as trainees try to explain how they imagine their role as mediators.

Regarding the institutional landscape, the trainees seem to identify the area of "logic," in which there are "directors" and "actors who shut the doors," "knowledge," people who are ahead of others and "racism." When referring to the place where mediators have symbolic control, they refer to the "bridge between logic and absurdity" and the people who can open the intermediate doors separating the different spaces. Their perceptions change once more as their thoughts go to places of resistance and internal discrimination, in which the community is "weak," "illiterate," "has anger," "is abusing drugs," "is sick," does not have the required courage, and is suffering from racism, and in which some members of the community "cannot follow some other people."

They also imagine themselves as community mediators, in which they will have symbolic control – a role that, on the one hand, will improve their own social and cultural capital by becoming a "model" and, on the other hand, will serve their "race," which they perceive as not having advanced, and which must acquire "a better life" and "evolve."

According to van Baar (2018, 7), this postcolonial, developmentalist logic is based on the discourses produced by several of the main developmental programs of the EU, the World Bank, and the Open Society Institute. These programs include the "Decade of Roma Inclusion 2005–2015" and the "EU Framework for National Roma Integration Strategies up to 2020," both of which suggest that, after passing through various stages on a continuum, the currently "underdeveloped" Roma will gradually join in with the "developed" majorities.

Adding to what van Baar claims, the Roma mediator programs seem to be built on exactly this logic, by using the mediators as the "human link," and the "bridge" between these two worlds. As a result, this imagined role by the trainees seems to rely on the power given to them by the intermediary space created by these programs and the mainstream racist consensus narratives[3] that they have internalized regarding Roma, who have "remained back," and non-Roma, who are ahead and have a better life and greater knowledge.

The internalization of these racist discourses and consensus narratives by Roma themselves, which, as mentioned above, creates the power of the intermediary space occupied by mediators, ties in with Bourdieu's concept of "symbolic violence" (Bourdieu 1990; Bourdieu and Passeron 1977), which has central importance in understanding the reproduction of inequalities between the social classes. For Bourdieu, "symbolic violence" represents the way in which people play a role in reproducing their own subjugation through the gradual internalization and acceptance of those ideas and structures that tend to subdue them. It is an act of violence precisely because it leads to the limitation and subordination of people, but at the same time it is symbolic, in the sense that this is achieved indirectly and without obvious and explicit acts of violence or coercion (Connolly and Healy 2004, 15).

3 For relevant references that reproduce such narratives, see Zagora 2015; European Western Balkans 2016; United Nations Human Rights 2018.

Similarly, the trainees seek to improve their economic, social, cultural, and symbolic capital by helping their communities, but at the same time they seem to ignore the fact that their role is based on the consensus narratives of the ideas and structures that subordinate them.

However, it is noteworthy that one of the four trainees (trainee D), provided a slightly different perspective on what a mediator is. More specifically, she imagined her role to be related with the "information on rights," the "solutions," and the "software" of society that will fight racism. Thus, as opposed to the rest of the trainees, who mainly reinforced the consensus narrative of the weak Roma, as well as the trainers who failed to highlight this trap, she managed to provide another perspective. Her words about the importance of fighting racism and the need to provide information to people about their rights added a totally different dynamic to the perceived intermediary space where the mediators have symbolic control. Today, as I reflect on these moments, I become aware of the huge gap left by the absence of critical approach theories during this training. Theories of critical Romani scholars would have probably allowed us to question these consensus narratives and, consequently, to cause a rift within the vicious cycle of the mechanism of epistemic violence against Roma.

The 'Trojan Horse' Mediator in Practice

More than a year after the training ended, I received a phone call from one of the trainees. He needed my support on a personal issue and he also told me that he was trying to find a job. An approximation of the conversation that took place follows (notes were kept in my diary):

> Me: Have you started working on this program? Is it over?
> RHM: Uh, it's been a long time since we finished. It took only two to three weeks.
> Me: Ah, that short? Well, what did you do?
> RHM: We went from the one neighborhood to the other… [named neighborhoods], and we "gave in the air" [spread the idea around] that measles are "decimating" children. So, we were informed after about one or two weeks that there was an outbreak in Greece and told them that we would return in a couple of days to do the vaccines.
> Me: And how was it? Everything went well?
> RHM: Yes, we informed a lot of people and we managed to vaccinate many kids. The adults also wanted to get vaccinated, but they told us that there are not enough vaccines.
> Me: And what about your payment? Did you get paid well?
> RHM: Money? Haha. Just a few. I do not remember well… wait, I can ask my wife… yes, I was given 180 euros. But, you know, I would do this even without money, for our children's health.
> Me: And what would you say in general about this experience?
> RHM: Do you know what came to my mind? I remembered what you told us at the training regarding the mediators who get turned into Trojan Horses. It seems that they [meaning key people from the ministry of health] remember us only in cases of an epidemic outbreak… when we become a front-page story on the newspaper and "their ass catches fire,"[4] only

4 Greek idiomatic expression that means that there is a state of emergency.

> then. They come for a while, they use us to do their job, and then they forget us until the next time. How is it possible to change things like that? Not to mention about the "leadership" that exists in these programs… How can you find the way out? Do you know how much money is there? Do you know how many have gone into these jobs without being trained? A few days ago, "my people" called me on the phone to ask me to attend this meeting. I told them I had a job to do and that I could not go. I do not want troubles with this kind of job.

Based on the above anecdote, it seems that even though trainees are taught to avoid the "Trojan Horse" mediation model – an instrument of the institutions, which aim to reach out to the community in order to change the attitudes and behaviors of its members (Rus, Raykova, and Leucht 2016, 11) – in practice this is not very easy to do.

According to the literature, "Trojan Horse" mediation is applied when mediators are employed by the authorities in an attempt to "buy" peace in the community, defuse potentially explosive situations, and shift responsibility away from the very people whose autonomy they are supposed to be fostering (Liégeois 2013, 7). Also, it is used as an excuse to avoid direct contact with the community, when community members are expected to shoulder full responsibility for solving problems (Kyuchukov 2012, 375), and as a "shield" or "buffer zone" between often intransigent public authorities and Romani communities, which may resent such "forced" interventions on their behalf (Clark 2018, 192) within health promotion as well as in improving access to educational opportunities. The reasons why mediators eventually end up acting in some cases as "Trojan Horses" include their low social status, their precarious employment conditions (low paid, temporary, and uninsured jobs), and their dependency on their employer (Open Society Foundations 2011, 37; Kyuchukov 2012, 375–6).

Likely, the fact that we had the chance to discuss the "Trojan Horse" mediation model during the training helped the trainee to critically approach the terms under which he had to provide his services during that project. As he mentioned, he realized that key people remember them only in emergencies, that they use them only when needed, and that afterwards they forget about them until the next time. I remember that during the conversation I felt glad that this trainee had questioned this project. Thinking about this conversation now, Spivak's question "Can the subaltern speak?" comes to my mind (1988). In the context of this anecdote, it seems that the trainee, even as a "subaltern" RHM himself next to those who made the decisions on the project, remained aware of the traps. Probably this is why he made the decision to "speak" – that is, to resist – by not attending the meeting with "his people" about "this kind of job."

'Hprolipsis'

A few months before the RHM training course was completed, I was invited to participate in the Hprolipsis survey – a Design and Development of Viral Hepatitis and HIV Infection Screening Program in the General Population, in Greek Roma and migrants. Among the study's aims was to estimate the prevalence and the determinants of hepatitis B, hepatitis C, and HIV infections in the three target populations. The survey was coordinated by the Department of Hygiene, Epidemiology and Medical Statistics of the Medical School of the NKUA and conducted in cooperation with several other actors. Hprolipsis was initiated in May 2013 and completed in June 2016 (for more information on the survey, see Touloumi et al. 2020).

Anecdotes from two events that took place during the survey follow. The first concerns the disclosure of the program to Roma mediators and the request for their support in implementing it. The second has to do with a challenge we had to face during the implementation of the survey. The dialogue that appears with both anecdotes comes from notes I kept in my personal diary.

Under the Microscope of Science and Media

Following the briefing I received regarding the survey and its aims, I turned to some Roma mediators, including those who had just completed the health mediation training program, to ask for their support on design and implementation. The following is an approximation of a conversation that took place:

Mediator A: What did you just say? We are going to the camps to tell people that we are here to test you for AIDS? They will start pelting us with stones, and they will be right!

Me: Oh, no, obviously we will not explain it that way. Besides, this study is not just an AIDS test. We will inform the habitants about how hepatitis A and B, and the HIV virus are transmitted so they can avoid infections – and, in addition, we will offer individual counselling and referral to the health care system for all positive individuals.

Mediator A: Once more, what are you saying? People do not have food to eat and we are supposed to approach them and discuss hepatitis? They do not care, no matter if they are infected or not. They do not have a job, they do not have homes, they live with mice, and you are talking to me about something they don't even know exists.

Me: I understand your frustration and I accept your objections. But on the other hand, why do you underestimate the impact of an infectious disease? You think this is not an important issue? Moreover, at the meeting we discussed the researchers' common practice, the one in which they go to the camps, get the data they want, take some photos, and then leave. And we set as a precondition that we are going to help them in any way we can, such as food, clothes, health services in the field, for as long as we are conducting the study, and not just get what we want.

Mediator B: And what about the tumult that the results of the study may cause? What is going to happen if the percentages are too high? We will be once more in the front pages, in the news. They will burn us alive. No! That's all we bloody need: to provide proof that we may transmit diseases. No, no way. Forget it!

Me: But this study is not only for Roma. It is also for the general population and the migrant population. This is not made to stigmatize you.

Mediator A: That's what you say. How do you know what is going to come next? And what will happen if the Golden Dawn[5] get to us? And us, who will have supported you – who is going to save us from our people?

5 Ultranationalist, far-right political party in Greece (in Greek, "*Chrysí Avgí*"), which is regularly described as neo-Nazi by media and academic sources. Members of Golden Dawn have been accused of carrying out acts of violence and hate crimes against immigrants, political opponents, homosexuals, and ethnic minorities.

In this particular anecdote, the first thing I would like to highlight is the eventual involvement of the RHMs in implementing this particular survey. This happened despite the fact that neither they nor the members of their communities participated in its initial planning – and also despite their disagreements and the fears the RHMs had for themselves. Therefore, it seemed that the pressure we imposed on them resulted in the loss of their "neutral, objective, and impartial role," which, according to the relevant manuals, they are supposed to have (Plopper and Iancu 2005, 77; Rus, Raykova, and Leucht 2016, 14).

Today, when I recall the above dialogue, I wonder about several things. How has science contributed to "not fitting" Roma and migrants into the "general population" category? What consequences might such a disassociation entail? Who selects the types of programs implemented for Roma and based on what parameters? Why don't members of the communities take part in the design of the projects that are implemented for them? What kind of narrative do the media use when announcing the results of such programs?

According to Hajioff and McKee (2000), genetic disorders, reproductive health, and communicable diseases seem to be the main health topics investigated in the literature regarding Roma. This makes Kühlbrandt wonder:

> Who prioritizes these topics, and according to what rationale? Is the focus a result of previous research that has shown these areas as particularly important (and if so, in what way), or are they based on vague or stereotypical ideas of Roma as having a limited gene pool (based on endogamy and/or their common Indian origins), as particularly prone to bearing children, or as a threat to the health of others (as sources of infectious disease) (2017, 29)?

According to the scholar, there are two important points to raise here (*ibid.*). The first is that the literature on Romani health yields unsatisfactory answers to the above questions. The second, which is the most worrying, is that the gaze offered by the academic literature on Romani health tends to reinforce its own assumptions. As Kühlbrandt explains, this happens because, when a large part of the literature focuses on the above-mentioned health topics, they are likely to be seen as "objective" problems in Roma communities. Furthermore, she notes, nobody seems to be asking Roma communities what they consider to be their own health priorities.

Likewise, Trehan (2009, 63–4) notes that the statistics, reports, and various forms of literature on policy regarding Roma, most of them produced by academic, governmental, and nongovernmental organizations external to Romani communities, tend to cause asymmetries of knowledge-power (Foucault 1973, 2008) to (re-)emerge and (re-)consolidate. Also, this increases the chances for the perpetuation of epistemic violence, thus having profound implications on the autonomy and future of the "Roma rights" movement (Trehan 2009, 63–4).

In the anecdote described above, Romani community members are once more mainly treated as Objects of a project and not as equal Subjects and equal participants in discussions about the design and implementation of a program designed for them. This prevailing approach in public health programs

underestimates the knowledge and opinions of "subordinate" Roma and distorts the perception of non-Roma regarding the daily problems faced by Roma. Moreover, it minimizes the opportunities for Romani community members to influence the discourse produced for them.

Things appear even more alarming when media also get involved (Friedman and Friedman 2015), as they tend to reproduce racist narratives regarding "Gypsy" stereotypes (Csepeli and Simon 2004; Okely 2014) and the "Gypsy threat" (Loveland and Popescu 2015). In fact, these racist narratives create what Goldberg (2008) has called "racial neoliberalism," which is the discursive boundaries created through these narratives to distinguish between "worthy citizens" and those lacking neoliberal market potential, and who, as a result, are treated as being "less worthy," "dangerous," and "criminal" subjects.

Kóczé and Rövid (2017), who studied the case of the so-called child theft of "little Maria" from Greece, and in building on the notion of "racist neoliberalism," refer to the politics of "double discourse," which is built around Roma and which is the product of a neoliberal approach. As they argue, a "double discourse" is structured by two contradictory discourses addressed to different audiences (*ibid*., 695). One discourse makes limited references to integration, human rights, and equal opportunities, and the other, through mainstream media, depicts Roma as internal and subordinated "Others."

The mediators in the above anecdote, who have been working for several years in relevant projects, seem to be very aware of how the politics of "double discourse" is applied in practice and therefore of the possible risks related to this survey. Unfortunately, their initial resistance towards the idea of this survey did not prevent its implementation, but it at least planted, at that time, some seeds for self-reflection among the members of our research group.

The Native Informant

One of the biggest challenges we faced in Hprolipsis project was that its design did not include mobile units, which could be used to conduct interviews and take blood samples. Thus, when a public space was not available, such as a school near the settlements we visited, the RHMs had to search for families that would loan us their house during our visits. One day, I received a phone call regarding this (an approximation of the conversation that took place follows):

> RHM: We have a problem. We cannot go back to [area and family name]. They are asking for money.
>
> Me: What are you saying? This is not possible. We have to return in order to reach the sample we need. Also, we have to go back again some weeks later to give the results of the blood tests.
>
> RHM: I am afraid you don't really understand. This man is looking for me – [man who owns the house] – to beat me up!
>
> Me: But how did this happen? Did you tell him that we would give them money for their house?
>
> RHM: No, I did not tell him anything about money, but now he says that we are making money out of his home and that we are giving him nothing. And it's not just him. Some people in

> the neighborhood are circulating rumours that for every vaccination we do, we get money. The more people we vaccinate, the more money we earn. Also, that once again, money that should be spent on Gypsies are taken by Balamos [non-Roma], who are implementing programs, and by us who support you. What's more, I am constantly scared – if there are any side-effects from the vaccines, no one is going to save me. They will hold me responsible.

The above anecdote verifies once more the claims that Roma mediators have to do tasks that are not included in their job description (assigning additional minor tasks, providing day care, doing secretarial work, and so on) (Open Society Foundations 2011, 35; Kyuchukov 2012, 375; Wamsiedel, Vincze, and Ionescu 2012, 12; Schneeweis 2015, 95). In addition, it shows that the RHM is somehow obliged to put himself at risk, as he will be held accountable to the members of his community if something goes wrong.

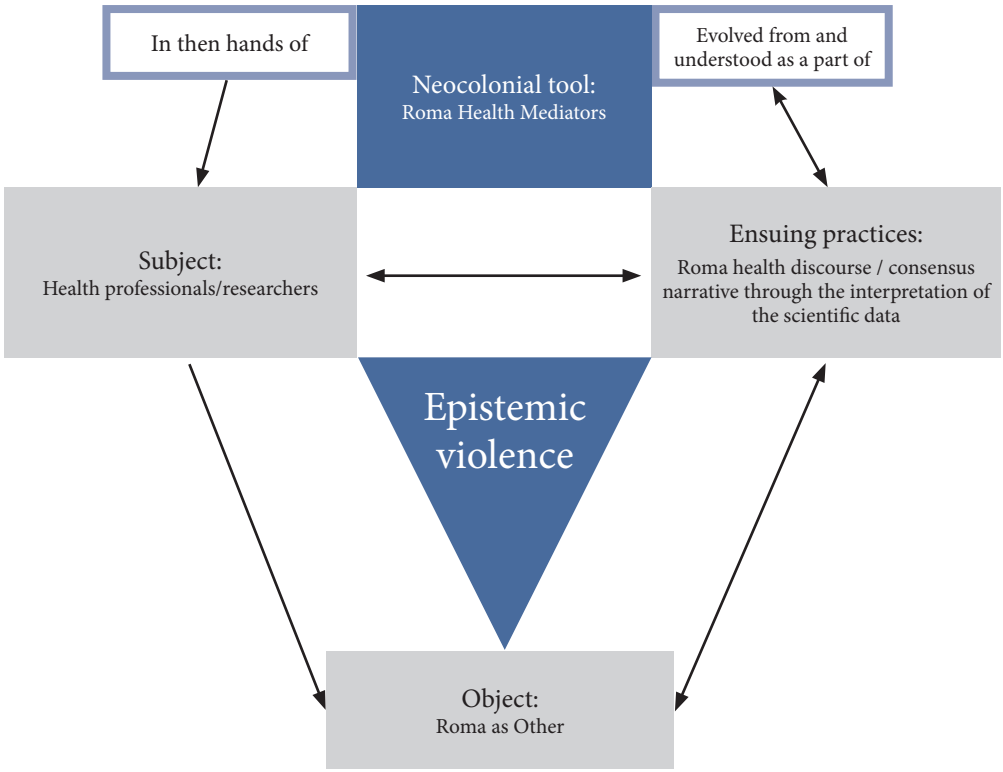
Furthermore, this anecdote also reveals the differentiated ways that the role of mediator is perceived, by those who invented the institution of Roma mediators and by the Romani community members themselves. For example, according to Kühlbrandt (2019, 2), during her fieldwork there was little to suggest that community members perceived the mediator as their ally; on the contrary, they seemed to associate her with town hall bureaucracy. In this case, the suspicions of some of the community members regarding the RHM's role are obvious, as they believe it allows him to "[make] money out of" the exploitation of the community ("The more people we vaccinate, the more money we earn"). In fact, community members associate RHMs with the people who take the money from programs implemented for Roma.

The suspicions brought to light in this anecdote, namely regarding the "profit" the mediator seems to seek through the risk that he puts himself in and the way in which his "traitorous" role is perceived by members of the community, remind me of Said's (1993) and Spivak's (1999) postcolonial concept of the "native informant." More specifically, the "native informant" is transformed into an "unreliable figure," (Ramone 2011, 140) as he is suspect of providing information and thus "betraying" his community. Spivak (1999, 6), in reviewing this concept, differentiates the native informant, who wears the costume of the "servant of colonial ethnography," from his modern incarnation, who, she claims, is masquerading as a native informant but is in fact a "self-marginalizing" or "self-consolidating" postcolonial figure. Thus, the native informant, either as an ethnographic tool, or as a literal figure of masquerade, remains needed and, at the same time, "foreclosed" (*ibid.*).

Today, I am wondering how different the design, the implementation, and the impact of this project would have been if we had replaced the colonialist logic of the expert researchers and their "native informants" with an approach that would transform the Object of the research into a Subject? Would there be a need for gatekeepers/cultural mediators who would have to walk a tightrope, balancing between "keeping faith" with their own ethnic group and facilitating access for the researchers (Condon et al. 2019, 7–8)? Would we have managed to earn the trust and support of the community members on our own merit? Would this have helped us, as researchers, to overcome the medical gaze and to deconstruct the consensus narrative on Romani health, through sharing the actual experiences of the community members (Wallengren and Mellgren 2015)? How could self-reflection have affected the whole project cycle management? What value could have been added by using a cross-disciplinary research committee?

While trying to answer these questions, I tried to imagine an opposite mechanism of epistemic violence to the one I described in the beginning, based on the work of other scholars and lessons learned through my own process of reflection.

Figure 1. The Mechanism of Epistemic Violence against Roma in the Field of Health



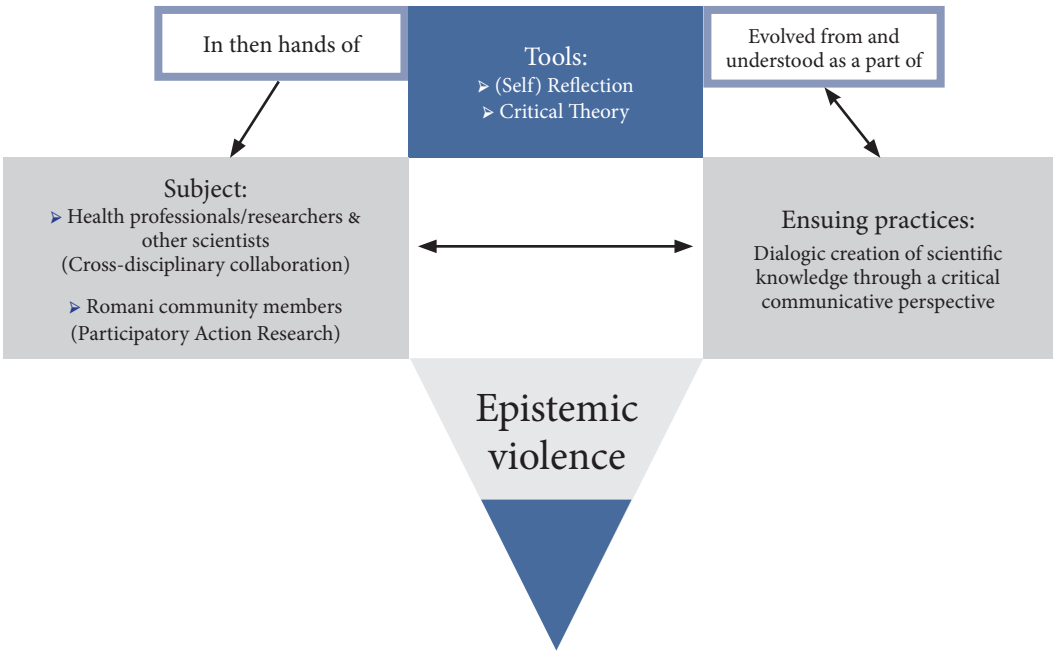
As a result, I started exploring participatory action research (PAR) methods, which can be considered as a social process that aims to transform both theory and practice. It can be depicted as a spiral of cycles of self-reflection (planning, acting and observing, reflecting, replanning, and so on), which has the following key features: it is participatory, emancipatory, critical, reflexive, practical, and collaborative (Kemmis and McTaggart 2005).

PAR seems to offer a promising framework within which to break down the objectification of the people being studied, and to involve those with whom the research is being conducted (Baum 2016). More specifically, according to Miranda et al. (2019), the PAR approach can instigate new alliances between and collaboration among multiple community stakeholders in spaces for equal collaboration, and thus to negotiate priorities and resources to be shared towards a collective goal. Also, according to Orton et al. (2019), although it is challenging, when done well, such an approach could contest and challenge definitions and lines of action decided by the researchers, thus leading to more courses of action and dialogical and reflexive knowledge production.

Based on the above, today I can clearly see the need for more competence development training on empowerment and participatory approaches for health professionals and researchers, as well as other scientists, policymakers, and decision-making bodies, as this would better facilitate our potential contribution in transformative processes and social change for all (Eklund Karlsson, Ringsberg, and Crondahl 2017).

Therefore, the use of PAR approaches (Greenfields and Ryder 2012; Bogdan et al. 2015; Eklund Karlsson, Ringsberg, and Crondahl 2017) as the furore surrounding the eviction has died down, the very pressing issues of accommodation need, inequality of access to education, healthcare and employment, and exclusion from British (and European research along with cross-disciplinary collaboration among those involved in different branches of science (Knapp et al. 2015), such as health researchers, cultural anthropologists, and policy makers, may reshape the idea of the Subject (to include professionals and researchers with different academic backgrounds, as well as Romani community members). This new form of Subject may put an end to treating Roma as an Object and RHMs as a neocolonial tool. Instead, the tools that may be used by the Subject are (self-)reflexivity and critical theory (e.g., Bogdan et al. 2015; Ford and Airhihenbuwa 2010; 2018) we issued a similar call to the multidisciplinary field of public health. Public health touts its progressive roots and focus on equity, but do those efforts draw on CRT? To answer this question, we define CRT, describe its origin in the field of law, and review the ways its use has grown in the field of public health. Public health interventions and policies rely heavily on evidence; therefore, we re-introduce the semi-structured research method we developed to facilitate empirical application of CRT, i.e., the Public Health Critical Race Praxis (PHCRP). Finally, the dialogic creation of scientific knowledge (Renedo, Komporozos-Athanasiou, and Marston 2017) through a critical communicative perspective may also help in further curtailing the production of the dominant discourse/consensus narrative regarding Roma. The depiction of such a "counter mechanism" to epistemic violence in the field of Roma health is presented below (see Figure 2).

Figure 2. The 'Counter Mechanism' to Epistemic Violence against Roma in the Field of Health



4. Concluding Remarks

In this article I critically approached the health sector as a field of governmentality that enacts epistemic violence against Roma. Also, I explored the potential, even if unintended, use of RHMs by health professionals and researchers as a neocolonial tool for the reinforcement of this epistemic violence against Roma. In particular, I argue that the epistemic violence against Roma stemming from the health sector is produced by the long-established interplay between the Subjects, which are the health professionals and researchers, the Object, which is Roma as "Other," and the ensuing practices, which consist of the production of discourse and consensus narratives through the interpretation of the scientific data. Based on the analysis of four empirical anecdotes, the potential is high for the use of RHMs as a neocolonial tool in the hands of the health professionals and researchers.

Specifically, this happens because their role may rest upon the consensus narratives of the ideas and structures that subjugate them. Furthermore, neither the context of traditional public health research within which RHMs usually work, nor the lack of competency in cultural and critical approaches by health professionals and researchers, provide enough space for RHM voices to be heard. Lastly, RHMs can be used as "Trojan Horse" mediators or even as "native informants," in this way re-establishing an "us versus them" mentality.

The countering by RHMs of the (most likely) unintended attempt by Subjects to use them for neocolonial instrumentalization is hindered by several factors. These include financial dependency; the desire to improve their social and economic capital; the fact that they are not members of the research team but rather follow instructions; and, finally, the limited power they have opposite the racialized dominant systems of power.

RHMs might also contribute to the neoliberal politics of "double discourse." The one discourse presents RHMs as an institution that supports integration. The second, contradicting discourse, through the use of RHMs in public health studies that do not really serve the needs of their communities and that disguise the structural oppression that Roma face, serves to "prove" that Roma are "dangerous" and "subordinated Others."

Even though top-down research, in which the researcher analyses, gathers data, and interviews the "Objects" of the research, is still dominant in the field of Romani studies, the emergence and dynamic development of Romani scholars, and their increasing use of critical approaches and theories, is gradually challenging the legacy of Romani studies and providing an entryway into new avenues of research (Dunajeva 2018, 125; Mirga-Kruszelnicka 2018, 21). Therefore, towards this direction, and as an obligation that we must all try to minimize as much as possible the epistemic violence within the health sector enacted against Roma, I suggest that cross-disciplinary collaboration, PAR, (self-)reflection, critical theory, and the dialogic creation of scientific knowledge are essential elements.

References

Abu-Lughod, Lila. 1991. "Writing Against Culture." In *Recapturing Anthropology: Working in the Present*, edited by Richard G. Fox, 137–62. School of American Research Press.

———. 1998. *Remaking Women: Feminism and Modernity in the Middle East*. Princeton, NJ: Princeton University Press.

Adams, Tony. 2015. *Autoethnography: Understanding Qualitative Research*. New York: Oxford University Press.

Albert, Gwendolyn, and Marek Szilvasi. 2017. "Intersectional Discrimination of Romani Women Forcibly Sterilized in the Former Czechoslovakia and Czech Republic." *Health and Human Rights* 19 (2): 23–34.

Baum, Frances E. 2016. "Power and Glory: Applying Participatory Action Research in Public Health." *Gaceta Sanitaria* 30 (6): 405–7.

Bobakova, Daniela, Zuzana Dankulincova Veselska, Ingrid Babinska, Daniel Klein, Andrea Madarasova Geckova, Lydia Cislakova, and HEPA-META team. 2015. "Differences between Roma and Non-Roma in How Social Support from Family and Friends Helps to Overcome Health Care Accessibility Problems." *International Journal for Equity in Health* 14 (April): 37.

Bogdan, Maria, Jekatyerina Dunajeva, Tímea Junghaus, Angéla Kóczé, Márton Rövid, Iulius Rostas, Andrew Ryder, Marek Szilvási, and Marius Taba. 2015. "Nothing About Us Without Us?" *European Roma Rights Centre* 2: 3–5.

Bourdieu, Pierre. 1990. *The Logic of Practice*. Cambridge, UK: Polity Press.

Bourdieu, Pierre, and Jean Claude Passeron. 1977. *Reproduction in Education, Society and Culture*. London; Beverly Hills: Sage Publications.

Clark, Colin. 2018. "Romani Activism and Community Development:" In *Community Organising against Racism: 'Race,' Ethnicity and Community Development*, edited by Gary Craig, 1st Edition, 185–98. Bristol, UK: Bristol University Press.

Condon, Louise, Helen Bedford, Lana Ireland, Susan Kerr, Julie Mytton, Zoe Richardson, and Cath Jackson. 2019. "Engaging Gypsy, Roma, and Traveller Communities in Research: Maximizing Opportunities and Overcoming Challenges." *Qualitative Health Research* 29 (9): 1,324–33.

Connolly, Paul, and Julie Healy. 2004. "Symbolic Violence, Locality and Social Class: The Educational and Career Aspirations of 10–11 Year Olds Boys in Belfast." *Pedagogy Culture and Society* 12: 15–33.

Council of Europe. 2016. "Final Report Endorsed by the Thematic Group of Experts CAHROM, Ad Hoc Committee of Experts on Roma and Travelers Issues (CAHROM) Thematic Report of the Group of Experts on Roma Health Mediators." Strasbourg, France.

Csepeli, György, and Dávid Simon. 2004. "Construction of Roma Identity in Eastern and Central Europe: Perception and Self-identification." *Journal of Ethnic and Migration Studies* 30 (1): 129–50.

Davis, Angela. 1981. *Women, Race and Class*. Reading, UK: Cox and Wymann.

Dunajeva, Jekatyerina. 2018. "Power Hierarchies Between the Researcher and Informants." *Critical Romani Studies* 1 (2): 124–43.

Eklund Karlsson, Leena, Karin C. Ringsberg, and Kristine Crondahl. 2017. "Work-Integrated Learning and Health Literacy as Catalysts for Roma Empowerment and Social Inclusion: A Participatory Action Research." *Action Research* 17 (4): 549–72.

Ellingson, Laura, and Carolyn Ellis. 2008. "Autoethnography as Constructionist Project." In *Handbook of Constructionist Research*, edited by James Holstein and Jaber Gubrium, 445–66. New York: Guilford Press.

European Western Balkans. 2016. "Roma Are Part of Our Union and Must Not Be Left Behind: EU Statement on International Roma Day," 8 April 2016. https://europeanwesternbalkans.com/2016/04/08/roma-are-part-of-our-union-and-must-not-be-left-behind-eu-statement-on-international-roma-day

Ford, Chandra L., and Collins O. Airhihenbuwa. 2010. "The Public Health Critical Race Methodology: Praxis for Antiracism Research." *Social Science and Medicine* 71 (8): 1,390–8.

———. 2018. "Commentary: Just What Is Critical Race Theory and What's It Doing in a Progressive Field like Public Health?" *Ethnicity and Disease* 28 (Suppl. 1): 223–30.

Foucault, Michel. 1972. *The Archaeology of Knowledge*. Translated by Alan Sheridan. New York: Pantheon Books.

———. 1973. *The Birth of the Clinic. An Archaeology of Medical Perception*. Translated by Alan Sheridan. London, UK: Routledge.

———. 2008. *The Birth of Biopolitics: Lectures at the College de France, 1978-1979*. Translated by Graham Burchell. Basingstoke, UK: Palgrave Macmillan.

Friedman, Eben, and Victor A. Friedman. 2015. "Network Discussion 1: Measuring and Reporting on Romani Populations." In *Romani Worlds: Academia, Policy, and Modern Media*, edited by Victor A. Friedman and Eben Friedman, 74–169. Cluj-Napoca, Romania: Council of Europe.

Goldberg, David T. 2008. *The Threat of Race: Reflections on Racial Neoliberalism*. Hoboken, NJ: Wiley-Blackwell.

Greenfields, Margaret, and Andrew Ryder. 2012. "Research with and for Gypsies, Roma and Travellers: Combining Policy, Practice and Community in Action Research." In *Gypsies and Travellers : Empowerment and Inclusion in British Society*, edited by Joanna Richardson and Andrew Ryder, 151–68. Bristol, UK: Policy Press.

Hajioff, Steve, and Martin McKee. 2000. "The Health of the Roma People: A Review of the Published Literature." *Journal of Epidemiology and Community Health* 54 (11): 864–9.

Kalaydjieva, Luba, David Gresham, and Francesc Calafell. 2001. "Genetic Studies of the Roma (Gypsies): A Review." *BMC Medical Genetics* 2: 5.

Kemmis, Stephen, and Robin McTaggart. 2005. "Participatory Action Research: Communicative Action and the Public Sphere." In *The Sage Handbook of Qualitative Research*, edited by Norman Denzin and Yvonna Lincoln, 559–603. Thousand Oaks, CA: SAGE Publications.

Kennedy, David, and Doug Mayhew. 2004. *The Dark Sides of Virtue*. Princeton, NJ: Princeton University Press.

Knapp, Bernhard, Rémi Bardenet, Miguel O Bernabeu, Rafel Bordas, Maria Bruna, Ben Calderhead, Jonathan Cooper et al. 2015. "Ten Simple Rules for a Successful Cross-Disciplinary Collaboration." *PLoS Computational Biology* 11 (4): e1004214.

Kóczé, Angéla. 2011. "Gender, Ethnicity and Class: Romani Women's Political Activism and Social Struggles." PhD diss., Budapest: Central European University.

———. 2019. "Illusionary Inclusion of Roma Through Intercultural Mediation." In *The Securitization of the Roma in Europe*, edited by Huub van Baar, Ana Ivasiuc, and Regina Kreide, 183–206. Cham, Switzerland: Springer International Publishing.

Kóczé, Angéla, and Márton Rövid. 2017. "Roma and the Politics of Double Discourse in Contemporary Europe." *Identities* 24 (6): 684–700.

Kostka, Joanna. 2015a. "Going Beyond Political Commitments: Explaining Diverging Outputs in the Use of European Structural Funds for Roma Inclusion Strategies in Spain and Slovakia." PhD diss., Budapest: Central European University.

———. 2015b. "Implementation of Roma Inclusion Policies: Why Defining the Problem Matters." *Social Inclusion* 3, (5): 78–89.

Kühlbrandt, Charlotte. 2017. "Containment: An Examination of Roma Health Mediation in Romania." PhD diss., London School of Hygiene and Tropical Medicine.

———. 2019. "Participation as Inclusion and Exclusion: Policing the Boundaries of 'Citizenship' in Roma Health Mediation." *Sociological Research Online* 24 (3): 430–43.

Kyuchukov, Hristo. 2012. "Roma Mediators in Europe: A New Council of Europe Programme." *Intercultural Education* 23 (4): 375–8.

Lefebvre, Henri. 1991. *The Production of Space*. Translated by Donald Nicholson-Smith. Cambridge, MA: Blackwell.

Liégeois, Jean-Pierre. 2013. *Developments in Mediation, Current Challenges and the Role of ROMED : Training Program for Roma Mediators*. Strasbourg, France: Council of Europe.

Loveland, Matthew T., and Delia Popescu. 2015. "The Gypsy Threat Narrative: Explaining Anti-Roma Attitudes in the European Union." *Humanity and Society* 40 (3): 329–52.

Marcus, George, and Michael Fischer. 2016. *Η Ανθρωπολογία Ως Κριτική Του Πολιτισμού. Μια Πειραματική Στιγμή Στις Επιστήμες Του Ανθρώπου*. Translated by Φώτης Τερζάκης. Αθήνα: Ηριδανός.

Matras, Yaron. 2015. "Europe's Neo-Traditional Roma Policy: Marginality Management and the Inflation of Expertise." In *Romani Worlds: Academia, Policy, and Modern Media*, edited by Victor Friedman and Eben Friedman, 29–47. Cluj-Napoca, Romania: Council of Europe.

Méndez, Mariza. 2013. "Autoethnography as a Research Method: Advantages, Limitations and Criticisms." *Colombian Applied Linguistics Journal* 15: 279–87.

Miranda, Daniela E., Manuel Garcia-Ramirez, Fabricio E. Balcazar, and Yolanda Suarez-Balcazar. 2019. "A Community-Based Participatory Action Research for Roma Health Justice in a Deprived District in Spain." *International Journal of Environmental Research and Public Health* 16 (19): 3722.

Mirga-Kruszelnicka, Anna. 2018. "Challenging Anti-Gypsyism in Academia." *Critical Romani Studies* 1 (1): 8–28.

Okely, Judith. 2014. "Recycled (Mis)Representations: Gypsies, Travellers or Roma Treated as Objects, Rarely Subjects." *People, Place and Policy* 8 (1): 65–85.

Open Society Foundations. 2011. *Roma Health Mediators, Successes and Challenges*. New York: Open Society Public Health Program.

Orton, Lois, Rachel Anderson de Cuevas, Kristefer Stojanovski, Juan F. Gamella, Margaret Greenfields, Daniel La Parra, Oana Marcu et al. 2019. "Roma Populations and Health Inequalities: A New Perspective." *International Journal of Human Rights in Healthcare* 12 (5): 319–27.

Petraki, Ioanna. 2014a. "Educational Program Young Roma Health Mediators Trainers and Presenters' Manual." Report. Athens, Greece: PRAKSIS. https://www.praksis.gr/assets/files/Trainers-and-Presenters-Manual.pdf

———. 2014b. "Η Κατάσταση Της Υγείας Των Ρόμα - Παράδειγμα Καλής Πρακτικής Συντονισμού Στο Πεδίο Αναφορικά Με Την Παροχή Πρωτοβάθμιας Φροντίδας Υγείας Σε Ρομά Παιδιά." Master thesis, Athens: National and Kapodistrian University of Athens. https://www.openarchives.gr/aggregator-openarchives/edm/pergamos/000005-_uoa_dl_object_uoadl%3A1311731

Plopper, Suzanne, and Daniela Iancu. 2005. "Training of Trainers Curriculum For Training Roma Health Mediators In Reproductive Health." Bucharest: JSI Research and Training Institute. http://www.romania.jsi.com/Docs/rfhi_rhm_tot_rh.pdf

Ramone, Jenni. 2011. *Postcolonial Theories: Transitions*. London, UK: Palgrave Macmillan.

Renedo, Alicia, Aris Komporozos-Athanasiou, and Cicely Marston. 2017. "Experience as Evidence: The Dialogic Construction of Health Professional Knowledge through Patient Involvement." *Sociology* 52 (4): 778–95.

Roman, Gabriel, Rodica Gramma, Angela Enache, Andrada Pârvu, Ştefana Maria Moisa, Silvia Dumitraş, and Beatrice Ioan. 2013. "The Health Mediators: Qualified Interpreters Contributing to Health Care Quality among Romanian Roma Patients." *Medicine, Health Care and Philosophy* 16 (4): 843–56.

Rus, Calin, Alexandra Raykova, and Christoph Leucht. 2016. "ROMED1 Trainer's Handbook." Strasbourg, France: Council of Europe. http://coe-romed.org/sites/default/files/documentation/ROMED1%20Trainers%27%20Handbook.pdf

Said, Edward W. 1993. *Culture and Imperialism*. New York: Alfred A. Knopf.

Schneeweis, Adina. 2009. "Talking Difference: Discourses about the Gypsy/Roma in Europe since 1989." PhD diss., University of Minnesota.

———. 2013. "Empowered Leaders and Alone in Community: Stories of Romanian Roma Health Mediators." *Women's Studies in Communication* 36 (2): 167–88.

———. 2015. "Power, Gender, and Ethnic Spaces: Geographies of Power in Roma Communities." *Journal of Communication Inquiry* 40 (1): 88–105.

Schwandt, Thomas. 1997. *Qualitative Inquiry: A Dictionary of Terms*. Thousand Oaks, CA: Sage Publications.

Spivak, Gayatri. 1988. "Can the Subaltern Speak?" In *Marxism and the Interpretation of Culture*, edited by Cary Nelson and Lawrence Grossberg, 271–313. Urbana, IL: University of Illinois Press.

———. 1999. *A Critique of Postcolonial Reason*. Cambridge, MA: Harvard University Press.

Surdu, Mihai. 2016. *Those Who Count: Expert Practices of Roma Classification*. Budapest: Central European University Press.

Surdu, Mihai, and Martin Kovats. 2015. "Roma Identity as an Expert-Political Construction." *Social Inclusion* 3 (5): 5–18.

Teo, Thomas. 2010. "What Is Epistemological Violence in the Empirical Social Sciences?" *Social and Personality Psychology Compass* 4 (5): 295–303.

Touloumi, Giota, Argiro Karakosta, Vana Sypsa, Ioanna Petraki, Olga Anagnostou, Agis Terzidis, Niki Maria Voudouri et al. 2020. "Design and Development of a Viral Hepatitis and HIV Infection Screening Program (Hprolipsis) for the General, Greek Roma, and Migrant Populations of Greece: Protocol for Three Cross-Sectional Health Examination Surveys." *JMIR Res Protoc* 9 (1): e13578.

Trehan, Nidhi. 2001. "In the Name of the Roma?: The Role of Private Foundations and NGOs." In *Between Past and Future: The Roma of Central and Eastern Europe*, edited by Will Guy, 134–49. Hatfield, UK: University of Hertfordshire Press.

———. 2009. "The Romani Subaltern within Neoliberal European Civil Society: NGOization of Human Rights and Silent Voices." In *Romani Politics in Contemporary Europe: Poverty, Ethnic Mobilization, and the Neoliberal Order*, edited by Nando Sigona and Nidhi Trehan, 51–71. London, UK: Palgrave Macmillan.

Trehan, Nidhi, and Angéla Kóczé. 2009. "Racism, (Neo-)Colonialism and Social Justice: The Struggle for the Soul of the Romani Movement in Post-Socialist Europe." In *Racism Postcolonialism Europe*, edited by Graham Huggan and Ian Law, 50–73. Liverpool, UK: Liverpool University Press.

United Nations Human Rights. 2018. "No One Left Behind: Mission Report on the Right to Housing and Related Human Rights of Roma in France." Geneva, Switzerland: United Nations Human Rights Office of the High Commissioner. https://europe.ohchr.org/Documents/Publications/NO%20ONE%20LEFT%20BEHIND%20ENG.pdf.

Van Baar, Huub. 2011. "The European Roma: Minority Representation, Memory, and the Limits of Transnational Governmentality." PhD diss., University of Amsterdam.

———. 2018. "Contained Mobility and the Racialization of Poverty in Europe: The Roma at the Development–Security Nexus." *Social Identities* 24 (4): 442–58.

Vermeersch, Peter, and Huub van Baar. 2017. "The Limits of Operational Representations: Ways of Seeing Roma beyond the Recognition-Redistribution Paradigm." *Intersections* 3 (4): 120–39.

Vivian, Carrie, and Lauren Dundes. 2004. "The Crossroads of Culture and Health Among the Roma (Gypsies)." *Journal of Nursing Scholarship* 36 (1): 86–91.

Wallengren, Simon, and Caroline Mellgren. 2015. "The Other Way Around: The Roma Minority's View on Doing Research on Sensitive Topics." *International Journal of Social Science Studies* 3 (4): 14–24.

Wamsiedel, Marius, Eniko Vincze, and Iustina Ionescu. 2012. "Roma Health: Perspective of the Actors Involved in the Health System – Doctors, Health Mediators and Patients." Bucharest: Romani Criss. http://www.romanicriss.org/PDF/raport%20final%20osi%20health%20_engleza.pdf

Zagora, Stara. 2015. "The Roma Left Behind." The *Economist*, 4 June.

Zampas, Christina, and Adriana Lamačková. 2011. "Forced and Coerced Sterilization of Women in Europe." *International Journal of Gynecology and Obstetrics* 114 (2): 163–6.

Zeman, Catherine L., Diane E. Depken, and David S. Senchina. 2003. "Roma Health Issues: A Review of the Literature and Discussion." *Ethnicity and Health* 8 (3): 223–49.