Genetic Studies of Romani Populations in Hungary

An Intersectional Analysis

By

Barna Szamosi

Submitted to

Central European University Department of Gender Studies

In partial fulfillment for the degree of Master of Arts in Gender Studies.

Supervisor: Professor Judit Sándor

Second Reader: Professor Dr. habil. Andrea Pető

Budapest, Hungary

2010

CONTENTS

ABSTRACT	III
INTRODUCTION	1
1. METHODOLOGY	4
1.1. Intersectionality: A Framework to Genetics	4
2.2. Expert Interviews with Human Geneticists	
2. BACKGROUND TO POPULATION GENETICS	14
3. ANALYSIS OF GENDER AND ETHNICITY IN THE GENETIC STU	DIES OF
GYPSY POPULATIONS IN HUNGARY	20
3.2. THE GENEALOGY OF ROMA IDENTITY	
3.3. GENETIC APPLICATIONS OF THE ROMA CATEGORY	
3.3.1. The Significance of the Genetic Genealogy of Roma Population	
3.3.2. Genetic Identification on the Base of Patronyms	
3.3.3. Ethnic Identity Based on Y Chromosome Research	
3.4. THE INTERSECTIONS OF ETHNICITY, GENDER, CLASS AND GENETICS	
3.4.1. Social Hierarchies in Gypsy Communities	
3.4.2. Role of Gypsy Males and Females in the DNA Sample Collection	
3.5. Issues related to the Roma Biobank	
3.5.1. Ethnic Categorization in Genomic Medicine	
3.5.2. Genetic Research on Closed Gypsy Communities	
3.5.3. Forming Roma Biosocialities	
CONCLUSION	47
BIBLIOGRAPHY	49

Abstract

This thesis focuses on the conceptualization of Roma ethnicity in the works of human geneticists. In my analysis I apply the methods of intersectionality and I use expert interviews to collect data. The collected material will be analyzed from a non-Romani feminist constructivist perspective. In the research of human geneticists the categories of diseases are at the centre and they link the Roma category systematically to genetic disorders. I argue however that this connection stabilizes the Roma category on a molecular biological level. This aspect fails to take into consideration the performative character of social categories. Geneticists by attaching the Roma category to a biological marker homogenize the culturally fragmented and diverse gypsy ethnicities and they reconstruct the gypsies' social structures along the lines of the traditional gender hierarchies.

Introduction

In the actual political context it is important to investigate the questions that are emerging from the genetic screening of Romani people in Hungary. The significance of this research can be explained with the geneticists' work, which aims at stabilizing the performatively constructed ethnic categories. An important conceptual slippage can be the reason why human population geneticists think it is possible to use a social category as reality. The imagined identity of the subject such as his/her ethnicity is reiterated through social practices hence it is not possible to justify a link between ethnicity and a marker on the genetic level. Ethnicity produces the biological (Lindee, 2003, p. 44), therefore biological phenomena cannot determine cultural meaning. In this present work my argument rests on the performativity theory (Butler, 1990) which states that all social categories are discursively constructed and the subject positions are performatively articulated according to the sociocultural context.

Class, gender, and ethnicity cannot be seen as constructing permanent fixed groups, but involve shifting constellations of social actors, depending on the ways the boundaries of a denoted category are constructed (Anthias, 2001, p. 378).

The argument implies that the intersecting vectors of the social categories construct subjectivities with permanently shifting emphasis and these processes produce the biological in every cultural context.

My case study is about the genetic screening of Romani population in different parts of Hungary. I use a project plan as a starting point in my research, which is entitled *"Romahealth": Classical and Molecular Epidemiology of Roma Population, A Pan-European Approach.* This project proposal was handed in to the European Union in 2007, and 10 European countries and India planned to take part. The main objective of the project is to identify genetic determinants both for non-infectious and infectious diseases in gypsy populations living in different parts of Europe. The project was not awarded funding from the EU therefore I analyze the work of geneticists who were part of the proposed project and continued their research on gypsy communities in different parts of Hungary in spite of the rejected proposal.

In this study I investigate to what extent is the application of socially constructed categories, such as Roma, class, gender and the category of ethnicity is possible in human genetics. The present work is based on the expert interviews that I conducted with the team leaders of different Roma-related genetics project. The aim of this work is to prove why it is mistaken and oversimplification to define an ethnicity with the phenomenon of SNP (Single-Nucleotid-Polymorphism) mutation and to reflect on the problematic practices of the human geneticists during the process of screening gypsy populations. I claim that they reconstruct and legitimize the traditional gender hierarchies during Roma DNA sample collection.

In this work I use the term gypsy and gypsies to differentiate from the term Roma, which is used by the human population geneticists. The term gypsy seems suitable for two reasons: the target groups themselves define their ethnicity with this category (Vlachian Gypsies, Beasi Gypsies), and the term Roma is not overarching at all from a gender perspective, because it only refers to male gypsy individuals. At least in this genetic frame, I think not only the fragmented and diverse cultural meaning disappear with the Roma category, but the emphasis is only on the male members of the ethnic communities.

The term gender means the division of males and females, the aspects of sexuality, the social hierarchies in a cultural context and the possible subject positions which can be mastered by a male and a female person. In this work I address the problems of gender division in the genetic research and the issue of gender hierarchies which are reconstructed in

the ethnic communities during the fieldwork of the human geneticists while they were collecting DNA samples from the members of the gypsy communities.

The scope of the work is very limited. This partly results from the nature of the subject and partly from the methodology that I chose to conduct the empirical research. The field of human population genetics is a closed research area, the scientists who conduct the research are the members of a small closed community. In the proposed *Romahealth* project eight Hungarian institutes intended to take part therefore I contacted the team leaders of the work fields. From eight contacted persons I could organize three interviews, which limits the results of the present work. Interviewing to collect material is not an easy choice, but this is the only possibility to gain insight into the thinking and everyday practices of the researchers of this closed field of human genetics.

In the second chapter of the thesis I introduce the methodological frame of the research. In the third chapter I give a brief background to human population genetics. In this part I primarily rely on the work of Luigi Luca Cavalli-Sforza (2000), because in my research I build on his isolation-by-distance model which is accepted by many researchers as the only possible explanation for the scarcely differing gene structures among humans. In the main body of the thesis I analyze the genetic studies of the Hungarian gypsy populations on three levels. I start with the social and genetic genealogy of the Roma ethnicity. The importance of the analysis is in the slippage in the use of the terminology in the different fields. From this part I move to analyze the fieldwork of the geneticists in the second subsection. This analysis deals with the ethnic hierarchies in the gypsy communities and their reconstruction by geneticists. In the third section I evaluate the issues related to the Roma biobank.

1. Methodology

1.1. Intersectionality: A Framework to Genetics

The theoretical and methodological works of intersectionality provide frame and conceptual tools in a feminist critical analysis on genetic discourse. A feminist approach to genetics claims that cultural norms should not be determined through the technologically mapped biology. Adrienne Asch and Gail Geller underscore that an intersectional feminist approach to genetics can help to find ways how to overcome on problematic views like: "biology is destiny, difference bad, and technological approach can be applied to study the genetic discourse related to the question: who is labeled as Romani in Hungary. According to Kathy Davis (2008) "the characteristics of a good theory are vagueness, open-endedness, incompleteness, haziness and ambiguity". This means a theory which successfully lends itself both to theoretical and empirical researches (Davis, 2008, p. 76). Although there is a big difference between the tools of scholars, it seems the open methods of intersectionality can give opportunity to approach theoretical works and to study empirical research at the same time.

Intersectionality with its complex and interrelated theoretical fields gives convincing frame for a gender analysis. The idea of complexity is also true for its methodologies. In the next paragraphs I will draw on McCall's (2005) article to give a description of the most important methods and I will evaluate them according to their usefulness in a broader research of structural and locational analysis in relation to the present research on genetic studies of Romani populations. This methodological differentiation is important from my perspective because I intend to draw attention to the anticategorical and intracategorical approaches, as I think these are the methods that will be useful in my further analysis. They are useful in connection to the categories which are applied by geneticists. The most important side of the present research is to point to the slippage between the meaning fields of the socio-culturally constructed categories and their applications by geneticists as realities.

The anticategorical complexity (McCall, 2005, p. 1773) which refers to a methodology that starts out from deconstructionism and it is aimed at deconstructing analytical categories. This view relies on the idea that social life is complex and it is in permanent change therefore it is impossible to fix or stabilize categories because subjects and structures are so fluid that they slip out of simple categorization. This approach is primarily important from the perspective of the individual, because the subject can identify with different social categories temporarily or can use identifications for his/her purpose but at the same time the subject can refuse to identify with a category that seems to be undesirable for him/her. This is a strategic move from the individual and it is done autonomously in a given context, but with the institutionalized use of the ethnic categories in genetics the socially constructed category become stable and makes it impossible for the subject to refuse to identify with it.

The connection of ethnicity with a biological phenomenon on the genetic level is meaningless because ethnicity is a term which refers to complex ways of lives which are continuously reiterated or refused to perform by the individuals, who might have the same genetic marker in their gene structure. This approach draws on the works of Michel Foucault, therefore later in my text I return to the Foucauldian notion of subjectivities when I map out the links between the process of subjectification and intersectionality. This approach rejects the use of political categories or identity labels but as I see this issue, practically there is no possibility to avoid these in a political discourse. What is possible and desirable is to balance the use of the categories in biology with their socially constructed meaning fields. The intracategorical methodological approach is important because I think it gives space to explore the social groups and individual subject positions at intersections and it tries to reveal the lived experience at the micro-level. This methodology does not reject the analytical categories: it rather supports the investigation of the processes of how we construct and define boundaries besides this method does not reject the stable relationships that are represented by social categories, but ask us to trace back the genealogies of certain categories and provide explanations on their connections at the intersections (McCall, 2005, p. 1773-74).

Nina Lykke (2005) claims, intersectionality as a conceptual tool is useful to analyze how power relations are interact in the discursive construction of categories such as gender, ethnicity, nationality, class. Lykke further argues, that it is necessary to emphasize that these categories not only interact with each other, because the meaning of the word refers to entities which have certain boundaries so that they are clashing against the other. On the contrary she suggests to use the term intra-action, this is an approach which entails that these entities are non-bounded therefore as it is involved in this definition these categories are not just clashing with each other but they mutually penetrate into the boundaries of the other (Lykke, 2005). I think the notion of intra-action is useful because the most important characteristic of intersectionality is the recognition of the mutual processes of construction and transformation of these social categories.

I agree with Lykke who sees the recently articulated concept of intersectionality as it is closely connected to the ways and methods how individuals or groups identify and negotiate their subject positions at the intersections of race, class, gender etc. As a result of global and local changes, both culturally and economically, the continuously intra-acting processes eroded the institutional foundations of stable identity formations and opened up the way to create multiple subjectivities. This process is unfortunately not only celebrated but some conservatives, nationalists and fundamentalists treated this phenomenon as a threat to their traditional existence and they fear the loss of stable anchor points. This traditional approach to identities does not put emphasis to social processes through which communities and individuals discursively construct their imagined identities. These socially constructed identities are passed to generations through socialization and became social realities, but it is necessary to understand that the meaning fields in biology are socially constructed realities always and they are always culturally determined, therefore they are performatively changing.

Here, I would like to elaborate on the individuals' capacity in relation to their identity formations because, as I see, in spite of the dynamic and constant change of intersections in the individual's life, the lived experiences show how individuals consciously shift the emphasis between the intersecting categories depending on the social situation. In order to strengthen my standpoint related to the subject positions created by the individual, I draw on the analysis of Dorthe Staunaes (2003). In her paper she sheds light on the connections of subjectivity and intersectionality. Staunaes analyzes the behavior of students in a school of Denmark. Her example is particularly interesting because in her study the focus is on the intersections of ethnicity, gender and age. As I see, this is interesting from the point of view of subjectivity formations because these children consciously articulate their subject positions in order to gain power.

Staunaes manages to show that the semantic fields connected to the construction of subjectivities are different for a Danish boy and different for a boy with a Turkish/Kurdish ethnic background and their difference particularly visible in ethnically mixed and homogenous groups. In my opinion it is vital to see that their emphases on the constructive categories are constantly changing according to the social situations. In other words an ethnic background is not an anchor point, it is not always in the focus and especially irrelevant in a homogenous group, where it does not function as an othering category. Ethnicity is always culturally attached to the body.

Staunaes (2003, p. 103) by realizing the importance of the methodological problem that is arising from the practices of the two main strands, the locational and structural intersectionality, suggests to investigate the relation of subjectivity, subject position in comparison with intersectionality. She compares subjectivity with identity (2003, p. 103) and concludes that the more useful idea is subjectivity because this notion can express stability and fluidity at the same time.

Subjectivity in the Foucauldian sense means that the subject in a cultural context can act in a way that the subject is active in creating its subjectivity; and the notion of subjectivity refers to the cultural contexts or discourses which constrain the subjects' possibilities. The subject is articulated at the intersecting vectors of discourses and this articulation of subjectivities is a two-way process. I think both of these are significant factors, the point made by Margaret Wetherell and Janet Maybin (cited in Staunaes, 2003, p. 103) is highly important: people in a group or alone on the individual level are not "cultural dopes." They are definitely active agents in the formulation of their lives, in relation to ethnicity for example, a person can continue to live life that is traditional, and be accepted by the members of the ethnic group, but it is the decision of the individuals to stop articulating their subjectivities in relation to the ethnic norms. As far as ethnicity is constructed through performative actions, the individual has the power to disconnect from the ethnic group by discontinuing the reiteration of the traditional way of life.

The idea of subject position is a powerful concept because it gives space to negotiate our social positions on an individual level. The concept of subject positions leaves the possibilities of the individual open in a socio-cultural context and I think this openness makes it possible to relate it to intersectional methods. Hence, in the following paragraph I will elaborate on the connecting points of an intersectional approach to the idea of subject positions. Staunaes' important contribution to the field of intersectionality is her suggestion to use the term "doing intersectionality." In her understanding, "this means the doing of the relation between categories, the outcome of this doing and how this doing results in either troubled or untroubled subject positions" (2003, p. 105).

The point what Staunaes makes (2003, p. 108) in her argument is the explanation of how agency works on the individual level. In her research she manages to shed light on the shifting character of power vectors. This means that the mechanisms are partly controlled by the individual as the subject has the power to refuse the identification with certain – generally uncomfortable – subject positions. This approach sees the individual as a subject who can act according to his/her will and capable of moving the balance in a power relation. In the case of ethnicity this is only possible if we understand the term as a category that is used to identify certain habits which are performatively reiterated from time to time. Ethnicity is performatively constructed through the acts of the individual or the community and an ethnic category is used by the ethnic community and by others in order to create social boundaries.

An intersectional analysis has to investigate "the differential ways in which different social divisions are concretely enmeshed and constructed by each other and how they relate to political and subjective constructions of identities" (Yuval-Davis, 2006, p. 205). I think Asch and Geller are right: a feminist critique of genetics is important "to identify the values that should refuse to surrender social meaning to biological fact and should insist on an inclusive understanding of community" (1996, p. 342).

2.2. Expert Interviews with Human Geneticists

In this research I take a feminist-constructivist approach to critically study the field of population genetics through the conducted interviews. Within social sciences the academic fields are divided concerning the question of a valid methodological approach. I accept the standpoint of Denzin and Lincoln (2003, p. 12) who underscore that there is no value free research; standpoints have to be taken, which eventually forms the results of the research. In this work the aim will not be objectivity, my standpoint as a feminist researcher is to critically analyze how social categories are applied as 'realities' in the works of geneticists.

The reason why I chose to conduct interviews is because this approach offers access to the most recent experiences of the researchers in the rapidly developing academic field of genetics. Population genetics is a very elite field in the natural sciences, not many geneticists working on the chosen project and it is not easy to get access to these researchers. I contacted the team leaders of the Hungarian institutes, who were interested in the Romahealth project, and from eight scientists, unfortunately I could only meet with three, therefore I could record only three expert interviews. This is partly the reason why it is necessary to treat the findings of the present study as very limited results. This research is a case study, approaches to case studies can be intrinsic and instrumental (Stake, 2003, p. 136-7). In this investigation the frame is instrumental case study, because the aim of the project is to provide insight into the issue of genetic definition of minorities.

Primary interest of the study is to understand the relation of the categories of social sciences to genetics. The case of the genetic screening of gypsy people gives possibility to give a critique on the approach to define a population through the categories of ethnicity and class, because this is the only ethnicity in Europe, which social position formed in a way that it is possible to identify them in every country where they live: the intersecting vectors of

class and ethnicity similarly create their marginalized social positions in every state in the European Continent.

To conduct interviews to produce data for academic analysis is a widely accepted method. In this case study the method of face-to-face interview is used. I apply unstructured questionnaires (Fontana & Frey, 2003, p. 48), the reason for this strategy is that unstructured, open ended questions are the only plausible choice for me if I want to gain data about the everyday experiences of human geneticists and want to get insight into their working methods. It is necessary to explain that I planned to conduct semi-structured interviews, but it turned out that it was not possible to relate the questions to the different fields of human genetics, therefore I asked the researchers to speak about their experiences in relation to the genetic studies of Romani populations in Hungary. I organized the analysis of their studies as they presented their fields and their results.

The interviews are recorded and transcribed through the use of a combination of the methodology offered by Anna-Brita Stenström (1994). Stenström deals with the methodology of transcribing and analyzing spoken interaction, it is crucial to record the data precisely, because the precise transcript helps to analyze the empirically collected data sensitively. To be able to analyze and to integrate the interviews into the body of the thesis I translated the recorded material from Hungarian to English.

The interviews will be interpreted through the method of thick description. I will analyze the collected data with the tools of intersectionality as in my view this can be connected to the features of thick description. As Rofel argues, thick descriptions are sensitive to the "contingent ways in which all social categories emerge, become naturalized, and intersect in people's conception of themselves and their world" (cited in Denzin, 2001, p. 99). But the concept of thick description entails many interpretational approaches. The most suitable for this study is the intrusive thick description. This method is open enough to allow the researcher's interpretation to form the description that s/he reports about. The researcher's point of view inevitably shapes the interpretation of the material in any case therefore I chose this interpretational frame because it allows the researcher to present the subject's perspective through his/her own eyes (Denzin, 2001, p. 111).

The definition of qualitative research can be described as a "multimethod" (Denzin & Lincoln, 2003, p. 2) in focus, which involves "interpretative and naturalistic methods" to study its empirical material. For a qualitative research the subject matter is collected empirically – these materials can be case studies, personal experiences, life stories, interviews and various visual texts (*ibid.* 2003). In an oral history research, not only the subject position of the researcher but the subject position of the interviewee have to be clarified, which means the issue of subject is unavoidable.

To conduct an analysis the researcher has to take into account the various feminist approaches to the idea of subject. In the formulation of my approach I draw on Weedon's article (2003) where the most important ideas on the subject are analyzed. For me, the liberal feminist subject is crucial. This view states that the subject is a rational individual, s/he is governed by free will, and hence this view cannot imagine the subject without agency (2003, p. 113). For a socialist feminist way of defining the subject, the most important categories are class and gender. Socialist feminist scholars are on the standpoint that class position and gender have key roles in the formation of subjectivity (2003, p. 114). These perspectives are inevitable for the present research, agency is crucial to be able argue that the subjects can articulate their lives autonomously and the categories of class and gender are necessary because of the geneticists approach to the traditional gypsy societies.

Judith Butler's performativity theory manages to entail the categories of class, race, gender, language, and discursive power relations which are constitutive in the formation of

subjectivity (Butler, 1990, Weedon, 2003, p. 127-8). Butler gives a very deterministic account on social life, and her argument excludes agency on the grounds of the reiterating practices of the community.

I take a constructivist liberal feminist standpoint to conduct my research because I think this approach both recognize the discursive practices on the structural level of a society and the contextual autonomy of the subject on the local level. This theoretical approach enables to ground the claim that the cultural practices are producing the biological phenomena.

2. Background to Population Genetics

The question of race has to be addressed in relation to contemporary studies of human populations. Problems related to racial categorization is heavily burdened by the race based eugenic practices of the 20th century's Nazism. The division between the different race based practices of the 20th century can be grasped through a look at the application of the theories which advocated the purification of the societies by the Communist and Nationalist political powers (Foucault, 2003, p. 82-3). The class-based arguments of the Communists were grounded similarly to the Nazi's, the important difference between their theories was that the racist arguments of the Nazi's were biologically based and were seeking for legitimization through eugenics.

The interchange of racial categories with ethnicities similarly has to be treated sensitively, this does not mean that ethnic categorization in contemporary genetic studies is racist, the whole meaning changed partly in consequence of the Human Genome Project. Genetic variability between ethnic groups is very low but is proved that different populations react differently to medical treatments which support the analysis of the genetic structure of human populations in order to improve their health. In the following I trace back the reasoning which lies beyond the supporting argument for the genetic studies of Romani communities in Europe.

Racial differentiation neither in social nor in natural sciences is not possible. Among many geneticists Luigi Luca Cavalli-Sforza (2000) provided an extensive analysis on the biological history, migration and evolution of the human species. In his analysis he argues that the first ancestors of humans were living in Africa around the Equator. In this theory this is the area from which all humans were coming from. Basically humans spread across the globe from Africa to Asia, from Asia to Europe and Australia and the Americas and Oceania between 100 000 and 50 000 years ago (Cavalli-Sforza, 2000, p. 94). The explanation for superficial human differences such as skin color, head shape or shape of the eyes is related to human adaption to different natural environments and the change of climate in consequence of migration (Cavalli-Sforza, 2000, p. 11).

In contrast to the tree-branching model, there is no valid explanation arguing for an original human group from which other sub-species date their ancestry, this is emphasized by Alan R. Templeton drawing on the works of Cavalli-Sforza et al., Templeton argues that the only option to explain human genetic differences is "the isolation-by-distance model" (2003, p. 244-5) which basically relies on geographic differentiation as this can be the only plausible explanation for the phenomenon that gene flow was obstructed by something, in this case physical distance, between communities which eventually led to present genetic differences among human populations. Genetic variation among humans can be detected by genetic tests when linguistic boundaries are creating relatively closed populations on a given territory, this argument is presented by Cavalli-Sforza (2000, p. 133-72) and it is applicable within the boundaries of a state as well. In a cultural tradition sub-cultural practices can create barriers within a state to obstruct free gene flow by prohibiting external marriages.

In the traditional Vlachian gypsy communities those members, both male and female, who marry to a person from the majority population, lose their membership in the community which they were born (Stewart, 1997). The individuals by denying the norms of the group and leaving behind the way of life that their people follow they are excluding themselves from their ethnic communities. These ethnic traditions shed light on the socio-culturally reiterated practices which basically re-formulated the ethnic boundaries of the community from time to time. These hardly visible cultural and linguistic dividing lines which still isolate ethnic groups in a given geographical area unavoidably shape the biological make up of a community.

The reasoning that those human populations who were migrating together for relatively long time shared their genetic structure is accepted by many researchers. This argument rests on the isolation-by-distance model, those people who were in the same ethnic group shared the same risk to get from the pathological gene which somehow got in the genetic flow of the community. A pathological gene is a gene that is mutated as a response to some kind of outside effect. This can be response to an environmental problem which is not easy to tackle for the individual or some other solution to health problems. It is important to note that mutation is the key to evolution while human populations were migrating they had to adapt to the various environments which enabled them to survive everywhere around the globe (Milunsky, 2003, p. 84).

However what is success on the ethnic or community level it can be a tragedy on the level of the individual. To take an example, the sickle-cell anemia is a mutation which evolved through time as a defense mechanism against malaria. In the territory where it is evolved there are much more new born children who get sick as a result of two parents who are carriers of the pathological gene. This problem was realized first in the United States, Troy Duster points out that in the US every twelfth African American is a carrier of the sickle-cell gene and 1 in every 625 African Americans gets the disease (2003, p. 269). From different results regarding genetic diseases connected to certain populations researchers argue that humans built a defense system in various environments and those individuals who lived in a community interchanged the genes of the group which caused and today still cause distinct diseases in communities, primarily because of the institution of close marriages. Those ethnic groups who had very strict rules for endogamy were the first populations which were examined (Milunsky, 2003, p. 84).

Among the first researchers on genetic disorders was Victor McKusick who collected data from the Amish communities of Pennsylvania in the 1950s and 60s. The Amish is a very

religious population who has strict rules for marriages and they are allowed cousin marriages which basically caused that many new born babies got the Ellis-van Creveld syndrome (Lindee, 2003, p. 43-44). The importance of this case lies in its strength that it managed to underscore the effects of marriages in a strictly closed population. This ethnic group was particularly significant because they kept the records of marriages and their relatives for religious reasons. So in this case the researcher who was primarily interested in this rare disease — the Ellis-van Creveld syndrome — came across the ethnic traditions of a community which even kept precise records about their in-group marriages. This provided the first scientific case for population geneticist that marriages with close relatives are key drivers in determining the frequency of genetic disorders in a community. The case study of McKusick clearly draws attention to the claim that "the cultural produced the biological" (Lindee, 2003, p. 44). Practices of ethnic groups can produce and reproduce biological phenomenon. The research on the Amish population proved that closing down the boundaries of a social group with cultural practices can lead to the high number of the same genetic disorder which was presumably a reaction of the body to a certain environmental challenge. This case study on the Amish groups is clearly related to the gypsy ethnic traditions which support the custom of endogamy. But in the case of the gypsy communities the reason for endogamy is partly stemmed from the exclusion of their communities from the societies.

Not only one ethnic community can have the same genetic disorder. For a mixed ethnic marriage disorder the most often cited example is the sickle-cell anemia of the African American population of the United States (Rose, 2007, Duster, 2003, Kittles & Royal, 2003). In their study Rick Kittles and Charmaine Royal (2003) highlight that slave traders kidnapped African people to the United States from eight major regions of Africa:

Senegambia (Gambia and Senegal), Sierra Leone (Guinea, Sierra Leone and parts of Liberia), the Windward Coast (Ivory Coast and Liberia), the Gold Coast (Ghana west

of the Volta River), the Bight of Benin (between the Volta and Benin Rivers), the Bight of Biafra (east of the Benin River to Gabon), Central Africa (Gabon, Congo and Angola), and the southern coast of Africa (from the Cape of Good Hope to Cape Delgado, including the island of Madagascar) (p. 219)

In spite of the contemporary political and geographical categorization of this enormous geographical area the kidnapped and eventually sold Africans came from many ethnicities. Their class position in the society of the United States created the closed boundaries of their communities. In this case the pathological gene was the result of the evolution of defense mechanism of the human body on the tropics where malaria was life threatening. This means that sickle-cell anemia as a disease primarily not ethnically, but environmentally related.

The reason why I cited the paragraph above from Kittles and Royal is to emphasize the ethnic diversity of the descendants of the African slaves in the United States, and to highlight its similarity to the homogenization of gypsy ethnicities within the Roma category. The ethnically different gypsy populations might share some kinds of genetic disorder, but it is a possible explanation in this case as well, that their genetic structure changed at the same historical time in the same geographical area as a response to the environment.

Among the first attempts to create databanks from genetic samples based on nationality was the Icelandic DeCode project. The population of Iceland was considered as a perfect community for genetic research because of its closed and relatively small nation (Rose, 2003, p. 81). Rose explains that the research was carried out as it was based on the individuals' nationality. The multiplex sclerosis disease was in the center of the research and the homogeneity of the group what made the Icelanders attractive to geneticists (2003). The fact that this genetic disorder was frequent within the boundaries of this ethnicity in this case literally meant complete physical isolation because of the geographic circumstances. The aim of this biobank project was to map the genetic structure and the genetic diseases of the population of Iceland based on citizenship.

The knowledge about genetic structures and their effects on the individual or an ethnic group, and the generally poor health conditions of the gipsy communities make important the complex genetic research on these population cohorts. People living in different geographical areas and leading different life styles developed distinct abilities related to skin pigmentation or digestion. Digestion in this case is a good example because milk digestion is the ability of every human person from the time of their birth but most of the human populations lose this ability by their age of five. The only exception is the Caucasian population because they were keeping animals and used the milk to make various foods out of it (Raskó & Kalmár, 2003, p. 110-1). It is worth emphasizing here that populations of Asia are among those who live with lactose intolerance and since different scientific fields including genetics agree that the gipsy populations came from India their genetic structure react to certain food differently (Béres, 2003, p.180). This also means that their genetic make up predispose them to different medicine and medical treatments so it has medical significance to tailor different programs and therapies to the needs of these individuals. And this is only possible with the mapping of the genetic structure of different gipsy populations.

Béres Judit points out that Y chromosome and mtDNA researches prove the North-Indian origins of the gypsy populations. However it is emphasized by her as well that genetic difference is significant between the Beasi and Vlachian gipsy communities which phenomenon could be explained with the ethnic custom of endogamy (2003, p. 180). This cultural practice is considered as the most important driver in the cause of distinct genetic diseases which are only present in certain populations. Closed communities without mixed marriages pave the way for the accumulation of a pathological mutation which eventually result in more frequently emerging genetic diseases.

3. Analysis of Gender and Ethnicity in the Genetic Studies of Gypsy Populations in Hungary

3.2. The Genealogy of Roma Identity

Travelling gypsy communities entered Europe through the Turkish Empire and spread across Eastern Europe from the Balkan-Peninsula in larger numbers only after 1453, the fall of Constantinople. Researchers from various disciplines (linguists, anthropologists, historians and geneticists) suppose that they were coming from North-India (Stewart, 1997, p. 27, Barany, 1998, p. 313, Liebich, 2007, p. 540-1, Czeizel, 2003, p. 64-5, Béres, 2003, p. 180). Since their arrival they were marginalized in every society where they appeared. Much discrimination occurred against them from the part of the majority population, to take an example they were enslaved in Wallachia and Moldavia until the second half of the 18th century (Crowe, 2008, p. 537-8). There are numerous gypsy ethnicities across Europe and they identify themselves differently, later in this section I elaborate on the fragmented characteristics of gypsy populations.

There is data which proves that the first empress and emperor who wanted to control the movements of the gypsy communities within the Habsburg Empire were Maria Theresa and then II. Joseph. They were the first who created laws in order to help but they rather enforced their integration into the majority population without much success (Czeizel, 2003, p. 65, Koulish, 2005, p. 313). The way how the peasants lived was against the gypsy way of life, they resisted to abandon their identity and become a *gazo* as it was expected by the majority population. The gypsies labeled the majority as *gazos* or *gazis* (peasant men and women) because of the life they lived (Stewart, 1997, p. 114-5). These identity conflicts were not solved by the societies of Eastern Europe neither in the 19th nor in the 20th century. As a

result of the eugenic thinking that became legitimized on the level of national politics. Between the two World Wars forced sterilization were institutionalized in Romania (Bucur, 2002), and in Hungary as well race-based ideology advocated the sterilization of the gypsies.

Stereotypes such as the gypsy people are lazy, they do not want to work, they do not want to take responsibility for anything, or they are dirty resulted in the deportation of the gypsies to death camps during the Second World War (Crowe, 2008, p. 522). But their struggle did not end after the war because when the Soviet troops occupied Eastern Europe and established communist governments the pogroms continued but in a different way. The communists wanted to integrate the gypsy population into the working class. In Hungary the period when Romani people were forced to take part in compulsory mass bathings because they were considered dirty and unhealthy were dated from 1945 to the 1980s (Bernát, 2002). After the transition many gypsy communities experienced rage, aggression and open hatred in many countries of the post-socialist block from the majority population. They were easy target to scapegoat and they never really had much power to defend themselves. Many gypsies left Romania for Germany because of the aggression they encountered in their state; and gypsy groups flew to Canada from the Czech Republic (Crowe, 2008, p. 523) as a result of similar attacks.

The gypsy communities were scattered across the borders of the nation states of Europe. They not only learned the language of the majority as it happened in the case of the Romungro gypsies in Hungary, but they mixed with the majority population while they were migrating. This means that they are not only diverse in their cultural habits but they are biologically closer to the majority population than to each other (Béres, 2003, p. 180). They differentiate themselves from other gypsy communities by identifying themselves as Beasi Gypsies, Vlachian Gypsies, Romungro Gypsies or Lovári Gypsies in Hungary only. But there are many communities which identify differently: Sinti, Servika, Manush, Kalo Gypsies, and Gábor Gypsies (Vermeersch, 2003, p. 882, McGarry, 2008, p. 449) and there are nineteen gypsy tribes for example only in Bulgaria (Barany, 1998, p.313). These groups are identified through religion and they are divided according to different territories. In the case of Hungary the members of the gypsy communities are generally catholic (Koulish, 2005, p. 316) they are not labeled according to their faith, however this is different in Kosovo and Bulgaria, where a large number of gypsies are Muslim and in Bulgaria they are labeled as Turkish Gypsies by the majority (Crowe, 2008, p. 521, 530).

The reason why I listed these different ethnic categories that the gypsy communities use to differentiate themselves from others is because it reflects on the fragmented, diverse and multi-layered cultural difference which is termed Roma. The constantly marginalized situation and discrimination of the gypsy communities made their intelligentsia to formulate their demands under a category which hoped to become easy for different gypsy communities to identify with. This means that the identification with the Roma identity from the different ethnic communities is rather a strategic move not an essentialist revelation of the gypsy communities at the turn of the 21st century. This idea of a common Roma identity is coming from different gypsy social movements, therefore it is important to emphasize that it is socially constructed and its meaning is rooted in the Romani language. It is meant to serve as a positive central point for gypsy groups across the borders to deconstruct the negative meanings that surrounded the different gypsy ethnic categories (McGarry, 2008, p. 449).

In the Romani language the word "Rom means human" (Stewart, 1997, p. 114), Peter Vermeersch claims similarly that the term Roma means man or husband (2007, p. 882), which meaning is important since Michael Stewart argues that this word has a feminine form Romni for woman or wife (1997, p. 208). The expression Roma is chosen to be used as category which is open enough to serve as a connecting point to many gypsy ethnicities, but it is worth noting that Roma serves as a traditional political category and it does not imply gypsy women. I agree with Brubaker's definition (cited in McGarry, 2008, p. 452) that "ethnicity is not a thing, an attribute, or a distinct sphere of life, it is a way of understanding and interpreting experience, a way of talking and acting, a way of formulating interests and identities" or in short "ethnicity is a way of life" (ibid. p. 450). Consequently this definition implicitly includes that ethnicity is performatively constructed, the *nature* of this reiterating process that the performative action is done by the individual and the ethnic group simultaneously. This is a dynamic two-way process in which both parties are active agents. The individual can refuse to identify with a certain political category by his/her will. And it is not surprising that many members of gypsy communities are afraid to identify themselves with their ethnic categories. These practices are experienced by geneticists: "we never ask from nobody if they are Hungarians or Roma. You can ask without any problem if they are members of any minority, and if s/he replies, so s/he can deny the answer" (Interviewee 1). In this example it is visible that geneticists experience that the people they meet sometimes do not want to categorize themselves as Roma. Reasons for refusing to use the category can be numerous, from fear to ignorance, or it is possible that they do not feel that they are essentially Roma.

3.3. Genetic Applications of the Roma Category

3.3.1. The Significance of the Genetic Genealogy of Roma Population

According to the *Romahealth* project, the genealogy of the gipsy populations is important because the knowledge that can be gained through this work can rearticulate the present approaches "to risk prediction, early detection and prevention both monogenic and complex diseases in different metagroups" (FP7-HEALTH-2007-A-2.1.1-2, p. 14). On the DNA level humans are fundamentally similar to each other, but differentiation among populations can be made based on the various DNA polymorphic markers which is different according to geographical regions. "This substructure is the blueprint of random mating originated from isolation by distance, language and cultural differences" (FP7-HEALTH-2007-A-2.1.1-2, p. 13).

In these studies the Y chromosome has key role because it is used as a marker to trace back the origins of a populations. These markers can shed light on the history of the migration of a given population. Based on these genetic studies the present data support the linguistic presupposition that the gipsy communities are originated from India. While they were travelling across Europe internal differentiation occurred in their communities which resulted in uneven distribution of diseases this is the reason why it is important to determine and categorize the genetic subgroups that posses numerous single gene disorders (FP7-HEALTH-2007-A-2.1.1-2, p. 14).

3.3.2. Genetic Identification on the Base of Patronyms

With the application of genetic technologies it is not possible to identify the Roma people, "it is not possible to tell from the genes if somebody is Roma or non-Roma" (Interviewee 1), it is not an easy task, though it may seems sometimes simple, as it is described by the Interviewee 1: "in many cases it is very trivial, so for example, we know that an 'Orsós' name is 99.99% Roma name, so the Hungarian majority do not use it. There are names undoubtedly which are used by both populations: 'Horváth' there are many Roma who is Horváth, but this name is similarly used by Hungarians as well, so you cannot tell them apart all the time sharply. In some case it speaks for itself, sometimes the person identifies himself/herself as Roma" (Interviewee 1).

But the difficulty of identifying the ethnicity of someone through their names is explained to me by the same interviewee later in the same monologue. When they researched people for Hungarian DNA: "we asked for samples from the majority, Hungarian majority, who were sure that their ancestors, at least from the last four generations, nobody were neither this nor that. To my biggest surprise, some of my colleagues told me: 'I give you my DNA with pleasure but there is Bosnian in the great-grandparent branch.' So s/he told us, s/he did not make it a secret, although his/her name is completely Hungarian." Although, as it is visible from the examples, this is not so straightforward, this practice is widely accepted by human population geneticists and this method is called patrilineal analysis of single surnames which is based on the custom that the father gives his name to their children.

This genealogical method of tracing family origins and group relatedness through the descendants of a father is only interested in males (Nash, 2004, p. 7). This methodology does not put emphasis on the fact that for reproduction both male and female parties are necessary, which means that the practice of researching surnames leave out more than the half of the population from the ancestors of a society. And a highly important aspect is that this genetic practice can reformulate on another biological level the masculinist perspective that women are not as good as men and they are not as important as men in the construction of a society. Identification of social constructs with biology, as identifying people as Roma by their names, can be appropriated by Radical Right Wing politics and used against populations easily.

3.3.3. Ethnic Identity Based on Y Chromosome Research

The surname analysis as a method gives ground to collect samples from the supposed relatives of men. The discipline which focuses on the common ancestors of different populations is called phylogenetics. These studies are investigating the biological phenomenon how information was preserved on the Y chromosome and the way it is transmitted from father to son. The structure of the Y chromosome barely changes through time. On a small part of the X chromosome the mitochondrial DNA similarly preserves information for long time. The study field is divided into Adam and Eve research by their focus on the chromosomes (Interviewee 2).

In this case because of the limited number of interviews I can only specify the problems which are arising from the Y chromosomes studies from a gender perspective. The reason to conduct Y chromosome analysis is the low information flow on these parts of the genes. "When the X chromosome joins the Y chromosome only small parts of them has connection where the gene flow can occur. Other parts, both the X and Y chromosomes keep their structure unchanged. And this makes it possible to do extensive long time analysis on relatives of the Y chromosome. It does not matter if populations mixed with each other the information on this part of the DNA are preserved" (Interviewee 2). When the joining of the chromosome is that its structure more easily changes in comparison to the Y chromosome. The information on this part of the DNA is subject to change more frequently. However the method does not leave space for women in the genealogy of a population.

Nevertheless the research on Y chromosomes is justified as this is the only tool at hand, which can determine the possible starting point of migration of a given population. "We research Y chromosome to find out for example how did a chosen Hungarian person's ancestors come to Europe" (Interviewee 2). And the method to get answers to these questions is the study of the changes (point mutations) on the Y chromosomes. "We detect SNPs [Single-Nucleotide-Polymorphisms] on the Y chromosome to trace back the history of these point mutations, and then with this method it is possible to follow the examined person's ancestors. These are unique mutation events, it happens once and these are population specific. And this is important in the case of Roma" (Interviewee 2). It is promising to research the Y chromosomes, because it "can be divided into ten major haplogroups, which

are the genetic variants of the Y chromosome" (Cavalli-Sforza, 2000, p. 156). These Y chromosome variants it is possible to trace back the place where the Y chromosome mutation occurred in a geographical area.

Through this analysis it is possible to define the date of migration and the date of the split that occurred in a population. "To define the dates of migration two mathematical investigations have to be done on the Y chromosome. The first is to study those markers which are mutating very quickly. And the second investigation is related to the SNPs. Based on the results of these two analyses, with the methods of mathematical statistics, we can define when that particular mutation happened" (Interviewee 2).

A point mutation (SNP) can be defined as a unique mutation and the other mutations are occurring frequently. And those men belong to the same haplogroup, a haplogroup is a term used for those people, who have the same SNP mutation. And there are mathematical programs that helps to determine from these two kinds of mutations, the time when did these mutations happened and when their common ancestors lived (Interviewee 2). These mathematical programs can give descriptions to the ancestry of a Y chromosome, but this method cannot answer the questions which are related to the matrilineal ancestry and the reproduction of a population. It gives answers to comparison of populations if they belong to the same haplogroup but if the answer is yes, I think it still does not mean that they share the same ethnicity.

This analysis can point to the geographical area where this SNP mutation happened and this method is able to give the date when the gene mutated, but this result is merely point to different groups, that shared the same living place and therefore gene flow could take place. In Europe, or in Hungary, before the great geographic discoveries the society was divided into two races (Foucault, 2003), the class of leaders and their subordinates, they did not mix with each other but in a social class the ethnicity did not really matter until the 15th century. The genetic similarity of the Hungarian population to the genetic structure of the Slavic people is an example how the Hungarian conquerors biologically assimilated when they settled down in the Carpathian basin. "Today, barely 10 percent of the genes in Hungary can be attributed to Uralic conquerors" (Cavalli-Sforza, 2000, p. 151).

Research on Hungarian samples show that when DNA were collected randomly from the citizens of the country "We found in the samples that H1 haplogroup is 7 percent in the total population and this haplogroup is the characteristic of the Indian population" (Interviewee 2). Or more precisely, it is not the characteristic of every Indian citizen, but "the H1 haplogroup is an ancient Indian population, and they are in India, at present, frequent in the members of the lower cast and the tribal groups" (Interviewee 2).

From this statement it is visible that the statistical analysis can only result in defining the geographical area where this particular H1 haplogroup is still frequent in the populations who live there. It cannot point to one particular ethnicity it is rather pointing to ethnicities who share the same Y chromosome mutation in different percentage in their DNA. And which occurred by some unknown reason, most probably as a result of a bodily reaction to environmental factors on a given geographical area.

Cultural change is relatively visible in comparison to the changes in the biological structure of the human body. Phylogenetic studies can contribute to the understanding of the change in ethnicities if the gene flow is understood as it has effect on the biological structure of a certain group and their customs. If an ethnic community opens up to other ethnic communities it is probable that mixed marriages occur which has effect on the customs, language use and genetic make up of the communities. By studying the Y chromosome phylogenetic studies could prove the supposed way of migration of gypsies through the Middle-East, Anatolia and the Balkans. "In our opinion, the Roma groups started to immigrate from India, they crossed the Middle-East, and then they went into the Balkans, and

from the Balkans its [the H1 haplogroup] spread across Europe. And while they were travelling they picked up genetic characteristics from the populations they met on their way" (Interviewee 2). The only reason why geneticists are still able to detect these characteristics is the exclusion of these gypsy communities from the society. This exclusion partly explains their frequent practices for endogamy, but of course their struggle to preserve their ethnicity is closely connected to family life (Stewart, 1997).

The haplogroups that they picked up during their migration are detectable in the Roma communities, because they live in closed/isolated groups. "When a group is isolated it is possible to see that the H1 haplogroup predominates the other haplogroups and this is the consequence of inbreeding, there is no gene flow into the group from outside and there is no out-flow" (Interviewee 2). The isolation-by-distance theory (Cavalli-Sforza, 2000, p. 196) can be applied in this case, because it argues that geographic distance causes genetic difference in populations. In the case of the gypsies the geographical distance is very low to the majority populations, but the cultural distance is a kind of isolation which explains their closed communities on various geographical areas across the European continent. The ethnic diversity of the gypsies can obstruct their intermarriages and the negative stereotypical attitudes of the majority population towards the gypsy ethnicities in the countries are enforce their isolation.

"With phylogenetic methods it is possible to define whether the studied groups had common ancestors or not. For example in the case of Roma, with the aid of network analysis we can analyze the genetic characteristics of Hungarian, Spanish and other Roma populations and it is possible to state that because of the few mutations (SNPs) they had the same ancestors" (Interviewee 2). This network analysis can be applied to point out if different ethnic groups shared the same SNP mutation and from the same SNP mutation it is concluded that they have the same origins, so they belong to the same ethnicity. But this analysis is not that simple all the time. "In the comparison of the haplogroup data of Hungarian Roma, with Malaysian-Indian, and North-Indian tribal groups, and Balkan Roma communities we could conclude that the Hungarian Roma people are genetically closer to North-Indian, and Malaysian Indian groups than to the Roma communities of the Balkan, in spite of the geographical distance" (Interviewee 2). This phenomenon is explained with the domination of the H1 haplogroup in the collected DNA samples, which is a result of long term inbreeding (Interviewee 2). Overall it looks as if the Roma category would be used as an equivalent of a single-nucleotide-polymorphism on the Y chromosome which is termed as H1 haplogroup in the discipline of human population genetics to cover all those people whose ancestors once in their history shared this genetic marker.

But not merely the reduction of the diverse gypsy ways of life into an SNP is problematic in this genealogy. With the Y chromosome studies an emphasis is put on 2 percent of a male person's genotype, this two percent serves as the ground to justify ethnic origin through patrilineal ancestry (Nash, 2004, p. 11). "Mothers are mere matter that transmit from father to sons the 'form, life and soul', and now genes, including the code for patrilineage and power contained within the Y chromosome (ibid. p. 11). In this new discipline women are seen, or women are treated as receptacles as it were in the Platonic tradition which defined Western thinking about women and their role in society for long time in history (Butler, 1993). With the re-appropriation of exclusive male importance in the constitution of an ethnicity geneticists "naturalize a specifically patriarchal version of kinship" similar to the religious genesis stories but this time it is based on biological data (Nash, 2004, p. 10).

Although in this case I had no possibility to analyze the results of possibly conducted mtDNA analysis, the results would not change on the claim that there is a slippage between the biologically used ethnicity and its social construction. And because the cultural produces

the ethnic categories it is impossible to find its equivalent in the studied mtDNA or Y chromosome mutation. It is necessary to underscore that the socially constructed realities which articulated in interactions are not possible to trace back to their *original* biophysical material. The application of Roma category as reality in genetics can lead to the biological stabilization of the various gypsy ethnicities on a molecular biological level.

3.4. The Intersections of Ethnicity, Gender, Class and Genetics

Different customs that characterize ethnicities and the gender hierarchies of an ethnic community, the social status of the group and the class positions of the individuals are shaped in complex interrelated ways. The socio-cultural factors of how the members of an ethnic group (can) lead their life; how they imagine a good life, effect their gender hierarchies and their class positions which determine their social capital. Basically both social and natural sciences agree that the previously listed factors affect a community's everyday lifestyle, customs and in this case most importantly: their health. In this chapter I point to the complex interactions which are forming the individuals' subject positions and their health status in the gypsy ethnic minorities of Hungary and how ethnic hierarchies are reconstructed and legitimized through the genetic screening of the members of different gypsy communities.

Ethnicity plays a significant role in the ways how an individual from an ethnic group can gain social capital (Shah, 2007, p. 29). In her study Shah further claims, that the class position of the individual is partly determined by the context where the person is born. The status of an ethnic group can influence social mobility of the person and the ethnic traditions which are expected from the members to be reiterated determine the gender hierarchies of the ethnic group, which eventually formulate the possible subject positions that females and males can master (2007, p. 29). Gender and ethnicity are central social categories and their significance lie in their role how they constitute difference, otherness and certainly subjectivities which are appropriated by many interest groups in a society and which eventually give frame or rather restrict the ways through people can gain resources (Anthias, 2001, p. 368), which has an enormous effect on the ways of life that they can formulate, so it is impossible to detach these central categories from the health of the individual or group access to health care.

Discrimination, marginalization, deep-poverty and insufficient education are power vectors that articulate the individuals health status and in this case it is necessary to point to their role in the formulation of the health status of the gypsy populations. These vectors are not single way forces but these are constructing the subject's health mutually at their intersections. In Hungary surveys were done "on the effects of multilaterally detrimental state on health status" (Aracsi, 2006, p. 108). These studies show the different vectors how they play key roles in the articulation of the health conditions of the socially marginalized groups. László Aracsi argues that the closest and directly affecting factors to health status are the family, socialization, environment, community environment, biological giftedness, social and material mobility, and lifestyle. The educational factor and income have direct and indirect effects on the individual's health status. And lastly the market position of the individual's labor force has indirect affect on health status but inevitably significant effect on income and lifestyle (2006, p. 118). These intersecting vectors mutually determine the health status of an individual or a group of people. Therefore the gypsy populations' health status is affected by many interrelating forces and it is primarily determined through the cultural sphere.

From these interrelating forces it is important to emphasize the effects of the family. Several social scientists argue similarly (Anthias, 2001, p. 383, Shah, 2007, p. 34) that the family is the primary site where the children learn the cultural traditions of the family, the gender hierarchies and internalize the values of the society. This effect is stronger in an ethnic group where the members live in a relatively closed community and the family functions as a model for the possible or desirable life ways for the children. Familial ties are very strong among the Gypsies. The ethnically defined man and woman in the gypsy communities have strongly divided hierarchies and their way of life is determined by their traditions, or if it is not completely determined it is very hard on the level of the individual to break out from his/her social position especially in a marginalized context.

3.4.1. Social Hierarchies in Gypsy Communities

Political organizations were established in greater number only after the period of transition. The leaders of these Romani organizations are coming from the elite classes of the Gypsy populations (Barany, 1998, p. 315). Although by the end of the first decade of the 21st century there are several transnational civil Romani organizations on the local level the hierarchies in the gypsy communities are still divided from the political sphere, or rather they have their own traditional political division. These sub-cultural fragmented, regional and ethnically different political environments made the geneticists to adapt to the situation if they want to conduct successful fieldwork.

The process how the genetic screening of the gypsy communities were planned and what kind of permissions were important is telling to understand the gender hierarchies in the targeted population. In this case the studied groups are the Vlachian communities in Szabolcs-Szatmár, Borsod and Hajdú counties in the North-East side of Hungary and there are examples from Baranya County, where the majority of the Beasi population lives.

In relation to the Vlachian studies, the geneticists had to organize the field works related to sample collection through different institutions, permissions were asked from ethical committees, and they established contacts with the Roma minority representatives and there were always a local minority representative who went with them to the field where the blood samples were collected (Interviewee 3).

Permissions had to be asked and contacts had to be established on many different levels. The point in describing the official work which prepared the research is to show the complicated ways how researchers could get to the field and when they were there these previously did steps would worth nothing if they did not negotiate with the local gypsy leaders. They contacted the mayors of the towns and villages to inform them what a group of human geneticists will work in that place. "And there was a town where a mayor told us to contact the local gypsy leader (the voivode), because the local minority representative is not identical with the minority representative who was appointed by the state. The social and political roles of the gypsy communities are based on their laws and they are differing from the official political roles" (Interviewee 3). This is a clear cut example how fragmented are the different ethnic minorities such as the Vlachian. There are places where the strong traditions to elect their own leaders are still alive and these practices reflect on their strong opposition to integrate into the political culture which is expected from them by the majority. This is a very similar opposition to the culture of the majority on the structural level they do not want to adapt the way of life how the gazo/gazi people organize their politico-social spheres.

The research team had to adapt their work methodology to the circumstances if they wanted to reach their goals. This strategy is politically correct they did not want to impose their values on these communities, but if they wanted to collect blood samples sometimes they had to ask the support of the gypsy leader. "So if we want them to help us, we have to convince someone who has [possibly: prestige, or power but the interviewee did not finish the sentence] to give blood and help to reconstruct his family tree, because it helps much more in overall, so this way it is more effective in reaching the aims of the project" (Interviewee 3). My aim is not to question the good intention and effectiveness of the methods, nevertheless

what is important here, is that these practices indirectly reinforced the power of some local leader. The political division is visible in other gypsy communities as well.

The Beasi Gypsy communities live in the Southern part of Hungary, in Baranya County. They came from the Balkans in a different wave than the Vlachian groups. They have different traditions and they use different dialect they do not mix with each other and they have different genetic diseases (Interviewee 1). In these communities it is similarly visible that they have their own social hierarchy and they have their own leaders. When they go in to the clinic the hierarchy is clear from their interactions, they have different kinds of leaders, for example "when he [the leader] is coming to the children's clinic, a colorful hat is on his head and some thirty people is coming with him" and it is clear from their behavior that he is the leader (Interviewee 1).

I think it is important to note that the company who is attending the gypsy leader goes with him, because the gypsy people believe that with this custom they make the bad spirits go away (Interviewee 3). But this custom rather gives insight into their social hierarchical structures, because when the leader's child is sick they are coming together which maybe an expression of solidarity but it also can be because of an order. I think the last option seems to be supported by the statement of the Interviewee 1, who claims that "it is visible as well that there is a strict discipline, what the leader claims, that is the way it is, and there is no other story. So that is the unquestionable law. Patriarchal structures are alive this is visible from the interactions." S/he further claims that this does not affect their research; they can collect samples without any significant problem, it is clear from the situations what they encounter in connection of working with them: their societies have their own system (Interviewee 1). Although I do not want to investigate legal problems in this thesis, it is possible that these hierarchical relations and the orders of the leaders in the case of these traditionally organized

groups make the informed consent highly problematic, because it is (ideally) based on the free consent of the individual.

What I would like to underscore in relation to the gypsy communities' social structures is precisely their patriarchal character: which many times mean what the elder male persons in the families want or the male leaders order in a community, that is the way how life should be (Shah, 2007, p. 37-8), and this is the way how women and children are deprived from their agency in a traditional ethnic community. In these cases we cannot talk about freedom, or free will, things are done by the subordinates (by women, children and men) because of the patriarchal hierarchical structure, and these patriarchal structures are legitimized in the ways how gypsy people interact with geneticists.

3.4.2. Role of Gypsy Males and Females in the DNA Sample Collection

In traditional ethnic groups the family is the site where both ideological transmission of the ethnic values and customs take place and in the family women as mothers play significant role both in transmitting the ideology of their culture and they are those who reproduce the members of the ethnicity: they act as agents who create the boundaries of an ethnicity both ideologically and materially (Shah, 2007, p. 38, Dimova, 2006, p. 308-9, Nash, 2004, p. 11, Yuval-Davis & Anthias, in Nagel, 1998, p. 252). These findings in connection to the gypsy ways of life are correlating in many ways.

In the traditional gypsy communities, men are constructed as healthy, strong and masculine, they often appear without wearing a cloth on their upper body, and the strength of the male members of the community is exhibited. However in contrast to the values of masculinity, femininity is constructed around the ideas of weakness and shame. Women have to be ashamed because of their body, gypsy men value those women, who are very modest and avoid displaying their bodies to the public (Stewart, 1997, p. 211-4). In following analysis

I intend to show how these traditional gender hierarchies are reconstructed through the process of genetic screening.

During sample collection, when the team of geneticists wanted to go into a settlement, the minority representative was going with them and sometimes a 'health guard' as well. "Community health guards have school leaving exam, and they were Roma women in these cases", so these Roma women helped the screening process because they mediated between the members of the group and the geneticists (Interviewee 3). It is important that the screening was helped by gypsy women, who were on the margins both of their and the majority's community probably they rather belonged to the majority than to their ethnicity because their way of life is different from the gypsy traditions.

Nevertheless, the role of these women seems to be important because they could communicate with gypsy women more easily, besides "they were responsible for the preparation of gypsy children for school in the community houses therefore they knew the families on the given place" (Interviewee 3). This means I think that geneticists had previous knowledge about the members of the families which they wanted to screen so they could map diseases of the population more easily with the help of the health guards.

The role of the women in the target group was basically important because a value of a female person is measured in the number of their children. Researchers experienced many times that the grand-mother had very important role in the community because not only her children counted but her grand-children as well (Interviewee 3). In this example it is clearly articulated, how traditional gender hierarchies formulating the success of the genetic screening of the Vlachian gypsy communities. Generally elder women in a family played key role in the project because they could influence their children to collaborate. "If a grandmother told to her children, that well I understand that you are healthy but you may have an offspring who [no end of sentence, possibly: will have a disease]. So please tell about the

diseases that occurred in your family" (Interviewee 3). This was the way how generally gypsy women contributed to the project. They were willing to describe their family tree along the lines of diseases.

The role of women is very similar in the Beasi gypsy ethnic groups. Women are dominating the spheres in connections to the tasks that are related to their children, women can negotiate in these situations (Interviewee 1). In the Beasi ethnic groups the male dominance is transparent in every social situation, but the site of child rearing is a typically female dominated sphere, where males give room for females to handle the context.

In the project, collecting samples from the Vlachian gypsy population, the attitude of males was positive but they generally claimed that they are healthy. "So it seemed that they did not want to understand what it means to be a carrier, they somehow denied the possibility of having a disease. They told about their healthy children or if they did not have they told us that they will have healthy children" (Interviewee 3). These experiences correspond to the traditional ideology how males should articulate their masculinity, how they should display their fitness to others. George Mosse points out in traditional communities masculinity is articulated along the ideas of physical strength, braveness; men were active while women were passive agents: women represented the guardians of the ethnic tradition (1985, p, 16-7). As it is seen in the example, they verbally demonstrate their fitness, through their reproductive abilities.

It was rare that they went in to get information about genetic screening, but sometimes it happened that they sat down separately with the few men who went in the doctor's office and the geneticist were able to ask about their family-trees (Interviewee 3). Overall, men kept the distance because the gender hierarchies of the ethnicity expect from them to be healthy and probably they socialized in their childhood to show bodily strength and healthiness to the members of the community. It is very probable that males construct their gender in their ethnic group according to these traditional ways, and these males if they would appear as weak they would loose face value and maybe their masculinity would be questioned by the community.

What is crucial in sum: males are the leaders, they allow outsiders close to the community, but it seems that in these cases as well, females have to construct their gender according to the traditional norm of the ethnicity. They have to be good mothers and take care of the health of their children and their offspring. This is justified by the answer of Interviewee 3, who explained that they were able to collect more samples from women simply because they were at home. They were more helpful and especially elder women, grandmothers had more power to influence others (mainly their own relatives) to take part in the project (Interviewee 3). And males pretended to be healthy and strong and because these males, who did not want to take part in the project could decide to do so (Interviewee 3), geneticists helped to re-create the gender divisions of the traditional ethnic community. Men could construct themselves to be seen stronger and healthier than women and women similarly performed the expected traditional gender positions.

The human population geneticist task is not to change the social hierarchies and gender relations of an ethnic community, and from the aspect of work efficiency it can be much more productive in many ways to show respect towards their sub-cultural societies and be familiar with their ethnic way of life and follow their rules. But it is needless to point out that with these practices they are reaffirming the hierarchical structures of these communities and the way how the members of the gypsy minority appropriate a new medical technology such as genetic screening, geneticists possibly reconstruct and legitimize the traditional gender division of their social structure.

3.5. Issues related to the Roma Biobank

3.5.1. Ethnic Categorization in Genomic Medicine

In spite of their different setting, different backgrounds, targeted homogenous or heterogonous populations, biobanks were created to serve the interest of the targeted groups of people, since in the long run, not only the individual, but the whole nation state and its ethnic communities will benefit from the results. Herbert Gottweis highlights that in the age of genomic medicine the goal is to provide personalized healthcare for everybody (2008, p. 23). From the emergence of the first biobanks such as the Icelandic, Estonian, Swedish or UK Biobank, the issues related to their aims and work were not without controversy (Sándor, 2010, p. 117-8, Gottweis, 2008, p. 22, Rose, 2007, p. 88).

The issue of biobank is crucial for complex genetic studies. One key element which forms the ground for complex genetic research is the biobank since large amount of biological material can be stored in these places. Within the frame of the Romahealth project the samples collected from gipsy individuals were planned to be stored in the Roma Biobank which is created to serve the interest of gypsy populations to prevent and predict diseases in order to improve their health. The biobank system planned to be a closed database serving the purposes of medical genomic research and the information about the participant is guaranteed to be secured. However there are legal problems emerging from information security since this terminology has different meaning in medical and in legal sciences (Sándor, 2010, p. 121), but in this chapter I will not analyze this issue. My aim in this part of the thesis is to argue for the importance of biobanks and to point to a possible and maybe desirable change in the present conceptual and methodological approach of collecting biological data from the members of the ethnically fragmented gypsy populations.

Racial and ethnic categories are present in the natural sciences in spite of the greatest efforts made by social scientists to highlight their constructed nature. Many contemporary social scientists (Valentine, 2007, p. 137, Anthias, 2001, p. 378, Butler, 1990) argue against the reduction of the socially constructed perfomative categories such as gender, race, ethnicity, or class to stabilized biophysical attributes of a person or a group, instead of taking into account the complex ways how the individuals understand themselves and create their own subjectivities.

Others argue that ethnic or racial categories are unavoidable in the age of genomic medicine and they serve can the interest of the individual (Rose, 2007, Duster, 2003). Not only different genetic disorders of a community make desired to use ethnic categories, but the results in drug tests in the field of pharmacogenomics prove that people living in different places of the world, or in the case of migration coming from different places of the world, make it necessary since for example they react to the same amount of a drug differently. These kinds of findings first made in relation to African Americans, they react to drugs differently than the Caucasians. Drug metabolism is different for example in the bodies of Chinese and Caucasian people, drugs have to be tested on Chinese people before it is marketed (Rose, 2007, p. 183, Duster, 2003, p. 258). Nikolas Rose further claims that other drivers in racial categorization are the biosocialities which made up of active biological citizens and their members are articulating their communities around a disease, at present they are articulating their advocacy groups around rare genetic diseases (Rose, 2007, p. 174). Research on ethnic groups with frequently occurring diseases is important because the health problems can be prevented through genetic screening. "When members of social groups with a strong endogamous tradition (such as ethnic or racial groups) intermarry for centuries, they are at higher risk for pairing recessive genes and passing on a genetic disorder" (Duster, 2003, p. 267).

At this point it is important to note that people with any kind of ethnic belonging can pair their recessive genes the point is if two carriers meet and their chromosomes are carrying

41

a genetic disorder, they join and they pass on their disease to their offspring. As human geneticists explain, humans can get the genetic disorder from both of their parents, but the ratio can be very different.

There are diseases that are connected to the X chromosome, such as hemophilia, or red-blindness, in which cases females transmit and males will be sick. This is because males have XY chromosomes their Y chromosome cannot balance a disordered X chromosome, while in the case of women a healthy X chromosome can counterbalance a disordered X chromosome (Interviewee 1, 2, 3). But basically the point is that parents transmit genes with the same chance, but the diseases are differentiated through their chromosome specifications.

In this case, it is important to emphasize that human geneticists argue for the generic, universal categorization of X, Y chromosomes and their pairing of the parents. This is important because the work of geneticists can be helpful for the gypsy communities in order to help their endogamous marriage traditions and to help them to avoid the birth of a genetically disordered child but the ethnic categorization I think is useful only in drug-related issues.

3.5.2. Genetic Research on Closed Gypsy Communities

Geneticists describe their approach of the target population as they primarily know the gypsy communities through diseases (Interviewee 1, 2). Their approaches to these ethnic groups are not from the social structural level, but they have contacts on the level of the individual. A pathological gene is the reason why a certain genetic disorder occurs in large numbers in a certain population, if a pathological gene (a mutation), gets into the gene flow of a community and this community is closed, this pathological gene gets concentrated. Therefore the possibility is high that two carriers meet in a closed community (Interviewee 1).

To collect data, the snow-ball method was used by the geneticist during their fieldwork. At the families, where the human geneticists went to collect blood samples, they described the families where sometimes three generations lived together. They primarily map the frequent communicable diseases in the targeted community. There are some visible diseases, like the Primer-convergalis glaucoma, which result in blindness in a very early age, therefore geneticists ask about others who have the disease in the community or they ask about other diseases in the family (Interviewee 3). With this method they can get information about the disease profile of the group which they examine. Finally they ask the family members to suggest another family that they know about where these kinds of diseases occurred (Interviewee 3). With this method it is possible to create a genetic map on the whole gypsy population of a given territory.

The family-trees are written down by the geneticists in a two step process. First the patient explains the diseases in the family and in the meantime s/he tells to the researchers the names of the persons who had some kind of disease. The second phase is connected to the General Practitioner: the geneticists go into the doctor's office and if the person [the patient] gave consent they are allowed to put down more precise data on the family-tree. It is important to note that if a researcher wants to have a representative sample they collect information randomly, but this is different in the case of geneticists because they ask every member of the family, and they ask about others in the community because anybody can be a carrier of a genetic disorder since it is not visible every time (Interviewee 3).

Through their research they map the disease profile a community and by highlighting the most common genetic disorders in the ethnic communities they are creating or rather pointing to the existing biosocialities but they are not activating the citizens of the ethnic community. They are claiming that the problem is that the citizens have little knowledge about issues such as genetic diseases, and "in connection to Roma people I would not say that it will be applied soon, because in many places they are very poor. They even do not know what to eat. Sometimes they eat potatoes for a week or just bread and butter. So they are struggling for survival day by day, this is not in their priorities" (Interviewee 3). Their marginalized social positions make hard for them to learn about genetic disorders and taking care of their genetic structure.

At the same time human geneticists (Interviewee 1, 3) are arguing for some kind of education about genetic counseling because the most important point would be to create a site for the gypsy people to get familiar with the findings of the researchers in a very early age to learn about the importance of genetics in relation to their personal life (Interviewee 1). It is emphasized similarly (Interviewee 1) that the problem is not that there are no institutional network which could not provide genetic counseling, the problem is the low level of informed people in general among the Hungarian citizens. Hence the goal is the organization how to distribute the information in the different gypsy ethnic communities in Hungary.

3.5.3. Forming Roma Biosocialities

In this part I argue that it is possible to prove from the interviews the terminology of ethnicity could be changed as far as genetic disorders are concerned. Those people who belong to the same group, who are carrying the genetic marker for a disease, form a group, which can be termed as biosocialites (Rose, 2007, p. 174) and these biosocialities can be seen as patient groups, which are fragmenting the genetic body of the state.

In my view the existence of biosocialities is not the question, undoubtedly it is necessary to map out these groups. But the focus should be on the diseases that they are carrying because primarily the name of a disease should be used to categorize the group, although the ethnic categories are still important but most probably only in the case of pharmacogenomics. In this aspect the arguments advocating the genetic screening of a population serves to change the paradigm of the clinical treatments.

The aim of genetic screening was to screen those genetic disorders which are possible to cure, but this ideological approach starts to change. Interviewee 1 points to the shift in the United States, where fundamentally the attitude of the society is what causes the change in the paradigm in the screening processes. The examples from the technologically developed Western countries, such as the US, are used as a reference point by geneticists many times: "This [paradigm shift] can be useful in many ways, because people can change their lives in order to spend more time with their loved ones or they can change their dietary habits and if they manage to gain time they have chances to find cure for their disorders" (Interviewee 1). But this is just one side of the issue. The other shift in the paradigm of clinical genetics is related to the therapies of the diseases.

"The contemporary paradigm in therapeutic method is the practice, if we are sick we get medicine to cure the symptoms, so the desired would be to get medicine for our genes" (Interviewee 1). But this contemporary attitude is start to change, researchers realized the first time in the US, that certain drugs had side effects for African American patients because their gene-structure react differently to drugs than the Caucasians gene-structure. The argument advocates change: "we should ask in the pharmacy medicine which fits our gene-structure, because if we take the same kind of drug it is not just ineffective but it can have side-effects as well" (Interviewee 1). These findings were the driving forces in Hungary to do population genetic studies in different regions and to include different ethnicities in these projects.

The reason for studying Roma populations in Eastern-Europe is that there were no such extensive studies on these ethnic groups before (Béres, 2003). Therefore it is important to know what kinds of diseases occur, and with what kind of frequency. These are molecular epidemiology studies in which it is possible to define the ratio of the carriers. The application

of these studies can be significant for example in prenatal genetics. This is a very important aspect because many diseases can be prevented so this program is good for the individual and for the community as well. So it is important to reach the level, that people gain knowledge about these things and go to have genetic counseling in their own regions (Interviewee 3).

"If a nation is smart they map their diseases. They map what kind of genes they carry and the ideal would be to screen the frequent mutations. An example, apart from Roma, non-Roma: in ladies, mutations that show susceptibility for breast cancer" (Interviewee 1). In this cite it is visible that diseases occur without relation to ethnicity, I am arguing in this sub chapter for the same practice. Apart from Roma, non-Roma the ideal would be to map the genetic structure of the citizens of a state. Ethnic categories are not important even in the case of marriages because what counts is the DNA marker if two persons are carriers they should not have a child because they unavoidably transmit the disease if they choose the traditional way of fertilization. But there are other options as well.

"If an unlucky situation occurs, when both partners are carriers, today there is the possibility of pre-implantation genetics, which means that fertilization should be done In-Vitro" (Interviewee 1). The goal would be in genetic screenings, to offer a possibility for the parents who are carriers to do the fertilization In-Vitro and in this way the will have a healthy child, who will be a carrier, but in this the child will not develop a genetic disease (Interviewee 1). From this argument it is clear again that the focus is on the people who are carrying the same genetic disorder, if they know about their genetic disorder they can prevent to have a child who have the disordered genes transmitted.

Conclusion

In my view the connecting point of performativity theory to genetics is the isolationby-distance model provided by Cavalli-Sforza (2000). Social boundaries are performatively constructed therefore the difference between gene structures is the result of the social distance between populations in a given geographical area. In this case in Hungary the genetic distance between the gypsy populations and the majority can be explained with social practices. In spite of the physical closeness, the social exclusion and the constant emphasis on the otherness of the gypsy ethnicities created the genetic difference which is at present possible to perceive on the molecular biological level.

Although in the research I had to rely on very small amount of empirically collected material, I think some limited conclusions can be drawn. In the main body of the text I analyzed the genetic studies of Romani populations in Hungary on three levels. In the first phase I provided a category analysis and I think it is plausible to state that the use of the sociological terminology in genetics is the reduction of the semantic fields of the concepts. In my view it is possible to understand that the category of Roma is intended to serve the health interests of the gypsy ethnicities in these researches but the result of attaching a category to these multi-layered ethnic groups through diseases simplify and homogenize their cultural diversity and stabilize these groups through a biological marker.

The Roma category is also problematic from the perspective of gender. The term denotes only the male members of the gypsy populations and from a linguistic perspective another problem is that in Hungary only, more than the half of the gypsy ethnic groups cannot understand the Romani language where the term is coming from.

Another important gender aspect was addressed in the second section of the analysis, which was the fieldwork of the human geneticists. Their work is mirroring the present gender hierarchies in their sample collection. Human population geneticists reconstructed the traditional gender hierarchies in the studied communities and legitimized their ethnic social structure within the state.

Creating Roma biosocialities is in contrast with the primary meaning of the term. Biosocialities (Rose, 2007, p. 174) are defined as the communities of active biological citizens, who organized themselves around a disease. In this definition there is no emphasis on ethnicity, the only important central category is the name of the disease which links these different people together.

The claim that "we primarily meet Roma people through diseases" (Interviewee 1) can imply that while samples are taken and the overarching Roma category is attached to the DNA, a new kind of citizenship, the Roma, is created through the mapping of their particular genetic disorders. The different gypsy populations which are homogenized as a consequence of this labeling process can be bounded through technological tools and genetic diseases as exceptionally unhealthy.

This process fails to recognize that their bad health is itself a cultural product: they are excluded from almost all spheres of the society. The mistaken link between biological phenomena on the DNA level and the Roma ethnic category can reinforce the present hostile attitude towards the gypsies across Europe in spite of the fact that this identity category was invented to serve their interests.

Therefore problem with forming Roma biosocialities is in the primary organizing principle: they are centered on the Roma ethnic category. The genetic disease mapping projects homogenizes and marginalizes the culturally, linguistically and geographically fragmented gypsy ethnicities on a molecular biological level.

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