ILLNESS AND MEDICATION THROUGH THE EYES OF THE ROMA PEOPLE IN THE CZECH REPUBLIC

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ABSTRACT
This paper concentrates upon Roma ways of dealing with illness from the perspective of social anthropology. Social science defines illness primarily as an opposite to the state of health. As such, it is to great extend a subjective and relative phenomenon, determined most of all by the native culture. Ethno medicine, a sub-field of social anthropology, offers for these purposes so called Explanatory model of Arthur Kleinman [9]. The author does not offer practical solutions in her paper. Rather, she points to differences and similarities in acting and thinking about illness by two different cultures, relativity of its validity in mutual interaction, as well as stereotypes that burden both teams of actors.

Keywords: Roma, illness, death, medication, anthropology

INTRODUCTION
Roma people, although they are living in the Czech lands since 1300[1] being part of the Czech society for several centuries, are still distinctively different from the non-Roma majority, *the gadže*. Such difference prevails due to strong endogamy of Roma people, causes of which have I discussed elsewhere [8]. As such they invade all areas of life, including attitudes to illness and health, methods of healing, as well as approach to death and notion of afterlife.

The Roma in the Czech Republic are rather a complex group that developed over the dense historical events during last two centuries [3], [4], [5] [6]. Most of the Roma traditionally settled in the Czech lands were exterminated by the Nazis during the Second World War [10]. The majority of the Roma living here today came during the last fifty years from Slovakia [2]. Today there are four different groups of the Roma present in the Czech Republic at the moment – Slovakian Roma, who comprise the largest group (cca 85%, 240000 people), Olach or Vlach Roma (cca 10% population and 10.000 people) and Moravian and Sinti (cca 5% population, less than 5000 people). Since all these groups have undergone different history of sedentarization and socialization into the *gadže* society, they have distinct views and values. Social scientists point to the difficulty to speak about the Roma as a single ethnic group within the Czech geographical context. Subjective Roma view upon these differences is also obvious when it comes to political representation of the Roma. Shared ethnicity is not a strong enough issue to attract both electors and electee).[2] As such, it is impossible to produce a single ´manual´, bearing witness about culture and values of the ´Czech Roma´.

[1] For a debate on exact arrival of the Roma into the Czech lands see [4], [5], [10].
[2] For broader discussion on Roma political representation and differences see [8]

Although we ought to approach all Roma groups as unique and different, they all share an important value of ritual purity, upon which the distinct Roma identity – *romipen* is build up. Several authors argue, that *romipen* is a key to understanding the Roma culture and ethos [2], [3], [13].

However, we ought to bear in mind that the distinct culture of the Roma is only one cause of the differences that prevail between them and the *gadže.* There is a visual, or even racial feature that enhances the difference too. Overriding social theories that stand at the background of Roma-*gadže* interactions have been discussed elsewhere [8], [13]. For the purpose of this paper it will suffice to state that the monocultural Czech society, created by the social engineers first of the Nazis (deportation of all Jews and Gypsies) and latter of the communists (post-war eviction of the German and Hungarian minority and isolation of the country from all but Russian influence for the next forty years) produced a community, where on one side there was a Czecho-Slovak white *gadže* member and on the other side the Gypsy/Roma minority member. S/he is the *Other* to the *gadže* in all the sense that Said [14] describes in his famous book, including bias and stereotyped behavior and expectation from the *gadže* population. The ideas of evolutionary development are key to understanding both the Said´s theory as well as current praxis of most integration and acculturation policies and theories of the Roma into the Czech society. Mainstream culture is seen as a norm that forms and restricts all other behavior. In this paper I wish to illustrate, what danger this mainstream understanding of illness may cause to Roma identity.

Notes on Czecho-Slovak Roma and research methodology

The number of the Roma people living in the Czech Republic is an estimate, comprised of opinion of local councils, regionally active NGOs and experts working in the field. Self- proclamation based upon shared Roma nationality, declared in the National census gives numbers dramatically lower.[3]

The core of my research was carried out during the longitudinal, a yearlong ethnographic research of Podlomy,[4] a small Roma village (1500 people) in East Slovakia. I have carried out a standard ethnographic research, based upon observation, interviews and secondary document analysis. All the notes and data has been then transcribed and analyzed according to the standards of scientific research. When reasonable, I have used the software Atlas.Ti.

The main aim of my research was to focus upon spirituality of the local Roma, their ethos, cosmology and believes. As an integral part of my work, I have attended many rituals such as baptisms, marriages, funerals and processions and interviewed repeatedly its participants. Although I have no professional medical training, simply being an educated *gadže* in a non-educated Roma environment torpedoed me to this expertise. My assistance to the families in question equaled to what we would call social counseling and common knowledge advice.

Once I have returned from Podlomy back to the Czech Republic, I had a chance to develop my research further. Numerous Podlomy families have close connection with my hometown, where (men especially) come to do seasonal work. My ethnography thus followed up the inhabitants of Slovakian Roma village in urban Czech setting. Once again, I was allowed to attend festivities connected with spirituality, where health issues proved a ´side effect´ of my aim. The character of these events proved different, since

[3] For detailed explanation see [8].

[4] All the names have been altered in order to protect identity of my informants

unlike in Podlomy where, given my gender, I was more a member of the female community, in Czech Republic there were mainly men present. That altered the subject greatly. From medical perspective, in the urban settings I have assisted mainly with work-related injuries and discussed pain of the heart (loneliness, adultery).

Due to historical development, Czech Republic is rather a mono-ethnic society, where difference is visible due to its absence. Roma people, the largest minority group in the country, are thus the most visible. They traditionally belong to the least educated lower strata of the Czech society, have darker skin complexion and their behavior and life is perceived stereotypically in accordance to these characteristics. To put it simply, there is a social (and often also spatial) segregation of the Roma people from the *gadže*. To large extend this is due to historical consequences as well as current active policy of the local councils and powerlessness (both on the side of their will as well as their ´know-how´) of the Roma to change it. There are only a few Roma individuals in public institutions on the side of the professionals, thus – since they are not seen in the professional sector, as if they would be ´non-existent´. It implies for all the public institutions, including the medical care. While meeting a doctor, a Roma person almost certainly has to meet a member of the *gadže* culture. Their interaction is simply not between a professional and a lay man. It is also an inter-cultural dialogue (or misunderstanding) as will be shown.

Anthropological perspective on illness and health

As pointed above, social anthropology proposes to look at illness as a holistic system of knowledge, which is a product of cultural history of a specific ethnic group or culture. Along this view, the western biomedicine is, such as it is practiced in most countries across Europe and North America, only one of the many medical systems used around the world. Because of that, we can undertake the same investigation into cultural history and validity of biomedicine as with any other non-European medical system.

Pluralist societies often accept several approaches to health and illness, while using a scientific treatment as well as naturalistic explanations; modern technology and surgery methods along the paranormal strategies with the aim to preserve life and soul. A mirror to these approaches is posed by humoral medicine,[5] whose whole idea is based upon the balance of fluids within the body of a man. Misbalance causes illness. Illness comes once we eat something bad, once the climate changes or once we are exposed to great influence of natural elements such as wind, water or fire. Wellbeing comes with restored balance. It can come from the inside (by eating pills and medicine), or from the outside (through a massage, exercise, acupuncture etc.). Humoral and scientific approach to medicine functions side to side in most countries of Latin America, Middle East, Indonesia and Philippines, just like the traditional Chinese medicine in China and Ayurveda medicine in India.

The key concept in ethno-medicine is the *Explanatory model* of Artur Kleinman [9]. It is a synthesis of information about causes of illness, criteria of diagnosis and possible methods of curing. It is often the case in clinical medicine that the professionals, the patient and her family offer and believe in different explanatory models. Communication that accompanies such encounter contributes mainly to the fact, that illness is described by two different languages: in scientific language and in

[5] For definition see e.g. ocp.hul.harvard.edu/contagion/humoraltheory.html; or phisick.com/article/humoral-theory/; both accessed on 7.7.2014

culturally/ethnically specific language. Very rarely happens, that one language overrides the other to the extent that believes, constitutive of the explanatory model, are changed by its speaker. Practically this means that if I offer a treatment to a person who does not agree with it, or regards her problem as rooted elsewhere, I cannot expect that she will follow my instructions regarding the procedures such as regular medication or rehabilitation exercise. Such misunderstandings occur regardless of knowledge of common language – or better to say – despite the common knowledge of language, since they are not rooted in the *parole*.

There are several studies available, commissioned mainly by individual hospitals and medical faculties in the Czech Republic, whose aim is to describe and characterize Roma people from the medical perspective through the eyes of the *gadže.*[6] Roma come out of these studies as follows: 1) They lead unhealthy lifestyle (bad and low quality food, high cholesterol, too much tobacco and alcohol, disproportional drug abuse). 2) They do not pay any attention to, nor use and take advantage of, preventive action (vaccination, etc.) 3) Among the Roma population, there is an above-average occurrence of chronic diseases (diabetes, high blood pressure, heart diseases). 4) Roma life expectancy is ten years shorter than among members of *gadže* population. 5) Roma show low awareness of family planning and gynecological diseases. 6) Roma seek medical help late, typically in the phase of emergency.

These are medical facts. Biomedicine recognizes their causes and labels them as unhealthy, worth of combating. It presumes that the quality of life improves for the Roma, once the problems will be addressed and actions will be taken to counter the causes. Such expert discourse offers active policies, whose aim is to acculturate the Roma in the discourse of European biomedicine. Not merely making the information available to them but rather making them to accept them as solely valid.

Roma culture within the last 50 years, on the other hand, proved remarkable resistance towards the pressure of centralized health system. Roma-regarding medical statistics today are not fairly different from those 40 years ago and the same issues are still discussed. One of the reasons for this is precisely the cultural construction of health and illness as well as its different ontological perception within the two cultures. What I wish to do now, is to look at some presumptions that lie behind the Roma understanding of health.

Roma understanding of health and illness

As mentioned above, Roma people traditionally seek medical consultation and help too late. They neglect prevention and their communication with medical staff is seen as distrustful and dishonest. There are many possible explanations to such behavior. Out of the many, I wish to concentrate upon cultural explanations of such conduct. First of all I will address the concept of polite refusal in Roma culture and later I will return to the concept of ritual purity and shame/ritual pollution (*marime*).

A cultural specificity of the Roma that has effect upon their interaction with non-Roma is a notion of polite refusal. It is considered rude to say ´no´, or to refuse in any direct way. Roma communication is heavily rooted in non-verbal communication. Should there be a situation when a Roma has a different idea about how things should be done, a polite way to communicate this to the Other is to be silent or to be vague but to express their true believe non-verbally. Should s/he be asked directly and be forced to

[6] Nesvadbová, L., Šandera, J., Haberlová, V. [11].

produce a verbal answer– the polite way to answer is to say what you believe the person posing a question wants to hear, regardless of what you really think or what you intend to do. In fact, in Roma culture it is considered rude to press somebody to answer directly a direct question. Naturally, latter behavior of this person does not necessarily correspond with what was verbally declared. *Eva*[7] *was diagnosed having stomach ulcers and the doctor advised her dietary changes, which she was not able to follow. Her problems worsened, she had great stomach pain and she was advised to undergo an operation, preceded and followed by similar yet even more strict diet, which she happily agreed to the doctor to keep. However, different behavior followed. The whole week prior to the operation she ate lots of meet, greasy food and drank lots of alcohol. Irena: Eva, you are having a wiener schnitzel for lunch? It is your operation day after tomorrow. Should you not be on a diet? Eva: How am I to survive an operation, if I will not be strong? I have to eat meat, it makes me strong and it will help me to survive the operation. I am so much afraid.*

This may be a possible reason, why Roma people are labelled as not-to-be-trusted or even liars by many non Roma, who are not able to read non-verbal communication that accompanies the verbal presentation. Mainstream Czech culture is much less skilled in non-verbal communication and professional communication of most areas relies heavily or even solely on verbal expressions. When forced to express dislike or refusal verbally in the context of hospital treatment, Roma patients often give child-like reasons – such as not having time to go to the doctor or not liking the food that constitutes their diet. In the eyes of the medical staff such type of reasoning supports the evolutionary persuasion of the mainstream hospital culture, where the doctor/nurse is the adult and the Roma is the child, which needs to be educated or even forced to adhere to the proper way of behavior. Nonverbal communication or cultural differences are not even considered an issue, doctors and nurses are not aware of the difference. Similarly unknown to the Czech medical staff is the concept to ritual purity and pollution.

Roma people traditionally divide a human body into two parts – upper and lower [7], [12]. that are to be kept separate in contact. The lower part of the body produces secrets (menstrual blood, urine, excrements and bodily fluids) that are considered unclean/polluting *(marime)* and thus are the source of shame and must be guided as highly private. Such division has daily practical consequences. To mention but a few: Utensils and other material objects (such as cloth and clothing) should be provided for two parts of the body separately. Different towels are used for lower and upper part of the body. Food, consumed by the upper part of the body, must not be washed in a space, where lower parts of the body are cleaned. Lower part of the body is not washed in basins, where there are upper parts washed. Once this taboo is not observed, the person becomes polluted and has a power to pollute others that come into contact with him/her. Pollution is primarily transmitted through physical touch and shared food. Non-Roma (*gadžo*) doctors and *gadžo* hospital culture do not observer the taboos of ritual purity and pollution. As such, they paradoxically symbolize a threat to the Roma, since they have a power to heal and to pollute at the same time.

Mainstream hospital culture rarely observes the concept of shame linked to gender. In Roma culture, it is considered shameful for a man besides a husband, to see a naked body of a women. Hospital grounds and a male doctor himself are thus a

[7] Paragraphs in italics represent parts of my fieldwork notes and interviews

potential source of pollution to Roma people and women especially. They are reluctant to speak to them about their intimate problems, pains and other health/body related issues. This leads to miscommunication between a male doctor and a female patient, resolving in dysfunctional treatment. While gender-sensitive and appropriate treatment has a long tradition among the Czech hospital staff in relation to Islamic or Jewish cultures,[8] that make up only a small proportion of patients in the Czech Republic, it remains a paradox, that such sensitivity is absent while caring for a female Roma patient. This is partly due to the fact, that professional texts about Roma and health - culture related issues are virtually non-existent in the context of the Czech Republic.

The concept of shame is also at the background of choice of clothing. While the mainstream culture allows for all sorts of clothing, including cross-gender style of dressing, Roma culture is much more traditional and Olach women especially have to wear skirts that cover all the legs down to their ankles. Shorter skirts are considered shameful for a woman, including a universal hospital knee-length gowns. Since their own clothing is – for hygienic reasons – not acceptable to the hospital, yet there are no long gowns available to the Roma either, a simple cultural difference often becomes an irresolvable problem. However, pollution is not solely linked to shame but also to illness. Roma people believe, that when the purity and pollution rules are not observed, a person not only becomes polluted but may develop a serious illness. Lasting non-health is thus seen as a punishment for breaking culture-bount rules of purity and pollution. S/He also becomes ´infectious´ - in a sense, that s/he may transmit the illness and pollution to others. Diane was one of my Roma friends who suffered cancer in Podlomy. Fellow villagers gave several opinions on the cause of her illness, all of them related to former *marime* status of her actions: "*Her husband loves sex. He forced her to do it all the time, even when she was marime (*understand menstruating*). This should not be done. It is why she is ill now" (Elsa).* Or other explanation*: "Emma, the youngest daughter, is not her husband´s. He was in jail at the time when she was born. Janko is her father. The illness is a punishment for her sleeping around. It is a dirty (marime) family" (Olga).*

At this point I have to make clear that the pollution and purity status do not necessarily correspond with general understanding of this word. Even a person that comes across as clean, kept and with hands ten times washed in an antiseptic lotion can be considered polluting by the Roma, should s/he not observed above mentioned rules. Let us put aside the concept of purity and pollution, shame and fear of the unknown and move a step further now, where I wish to describe, how serious illness (meaning a long-term illness that requires regular home or hospital treatment) is approached and lived by a Roma patient. At this point it is the ethos and cosmology of the Roma that is directly projected into the daily experience of different states of health and helps the patient as well as the society to make sense of a new situation.

As stated above, among the Roma we encounter a highly different perspective on what constitutes health and illness. Unlike among the *gadže*, where the natural-science explanations of illness prevail today, the key concept among the Roma is Fate. Illness is closely linked to negative Fate, while healthy are those, whom the Fate favors. Analytically, this is a very important information, since it has direct relation to the process of healing. To get healthy means primarily to make Fate to turn to you her positive side again. It can be stimulated by several spells, fetishes and actions that Roma

[8] First texts about gender-sensitive treatment of women observing Islam go as far as 1930´s – see [1]

tradition prescribes and that are integral part of healing. Process of healing is preceded by the process of searching through ones consciousness and realizing possible disagreements with members of community, finding possible bad deeds that influenced others. Once this phase is over, a healing process begins by counteractions. The patient – preferably by personal contact – tries to correct the bad deeds, to restore equilibrium in damaged relationship. Should I wish to exaggerate slightly, while non-Roma patient is already in bed, visits a doctor or takes pills and medicine, Roma patient is running about the village/community, using above mentioned methods to persuade Fate to return his/her health. Socialization that may have a positive effect upon Fate and thus directly upon health of a person is considered more effective process of healing by the Roma, than getting rid of physical symptoms of the illness. In the light of this fact we must interpret the answers of the Roma, declaring ´not having time to visit a doctor´ in a completely different mode.

Linking Fate to health has one additional vector. Once the patient´s health improves or when symptoms fade away (traditionally once antibiotics or other medication begins to work), the Roma stops acting as ill. She stops taking medicine regularly and returns to the former way of live. She does not share a belief for the medication to be the chemical stimulator of inner healing process, thus she does not accept the importance of regular and/or longitudinal need to take it. *Katka´s small daughter Lucy is taking antibiotics for her sore throat. After three days she felt well and it was difficult to keep her at home, while all the other children were running outside. Katka stopped giving her the pills and let her run about with others. In two days Lucy had sore throat again, so antibiotics was administered again by her mother. The whole situation repeated itself once more and little Lucy had to take a second dosage of the pills, since she was considered ill by the doctor once they went to the check-up a week later.* The vision of long term-improvement is less attractive than immediate involvement in usual style of living.

During my fieldwork I have repeatedly encountered situation, when life as a hospital patient was not considered fully Roma. As a consequence of this, it was not considered a quality life and people therefore tried to avoid it as long as possible, although at the same time they recognized possible fatal consequences. Diane, suffering from cancer, had to undergo a chemotherapy regularly. Instead of the hospitalization, she opted for ambulance care, which consisted of ninety minutes ambulance ride to the hospital every other day. Her reasons for this were following: "*In order to be able to live, I need to know what is happening in my village, in my family. I am a Roma, I want to eat our food, not the hospital food. I do not like it, I am not used to it. I do not know anybody in the hospital. I would die of loneliness the other day I would come there and no therapy would be needed. I need to see my people".*

Another important factor in Roma approach to illness is her family. Family traditionally plays the most important role in her life. It gives her status, identity and reason to live. Individuality is traditionally suppressed within the Roma culture in the Czech Republic. Without a family, she means nothing, she is nothing, she belongs nowhere. Okely [12] even declares that the Roma identity has its roots in acting as a Roma. It is not an inherent bodily quality or essence but rather it is a way of life and conduct. Prevention from such way of life (by illness or death) disqualifies a person from living a Roma life, or even from being a Roma. Rituals and actions that surround illness and death among the Roma are therefore directly responsive to this endangering situation.

Should a Roma become ill, at home or in a hospital, Roma people are visited by wide and numerous family, crowds of people standing beside their bed, on the corridor, outside of the hospital. Why is it so important? Roma culture is based upon a family unit with high degree of co-operation. Older siblings take care of the younger ones, extended family often lives, works and socializes together – a fact that is culturally and historically deepened by lasting spatial and cultural separation between Roma and the *gadžo*. Traditionally, they live in small spaces – be it originally wagons, latter small single-room houses and huts, today small flats in towns and cities. Human proximity in such space, including haptic contact – is much more frequent, compared to the *gadže*. Roma spends her life with the Roma, away from the *gadže*. Illness and hospital treatment takes all this certainty and proximity away and twists it around. Feeling of fear makes many Roma to run away from this situation. Possibly, that is why most opt for an ambulant treatment or simply run away from a hospital.

The wider family is the final decisive body for the medical treatment of a Roma individual. Not individually, but as a collectivity, the family decides about medication, possible operations and healing process of a Roma man or a woman. Every extended family has a head, an authority that is consulted in the time of crisis, makes big decisions. It may be an older woman, more often it is an older man, who is the guardian of family shame and ritual purity. As such, s/he has an important voice in decision making. At this point we can – once again – witness the complexity of the *Explanatory model* [9] mentioned above. In the Roma culture, it is not only the medic and the patient who come into dialogue about illness and treatment. It is also the family of the patient. When making their decisions, the family leaders must take into consideration and respect other dimensions of Roma existence, such as keeping the order, hierarchy and social borders.

Roma attitudes to illness and health are indeed different to that of the majority. My paper illustrated these distinctions that acculturation ambitions of mainstream healthcare system tend to overlook or disregard. It is my belief that this blindness is the cause of prevailing negative health situation of the Roma in the Czech Republic.

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