

THE REPRESENTATION OF DISEASE AMONG THE ROMA POPULATION IN NORTH-EASTERN ROMANIA

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REZUMAT. Reprezentarea bolii în rândul populației rome din regiunea de nord-est a României. În condițiile noilor provocări ale globalizării, grupul etnic al Romilor, considerat pe plan internațional o minoritate dezavantajată, la limita subzistenței, indiferent de țara de rezidență, este un permanent subiect de studiu în variate domenii științifice. Unul dintre domeniile reprezentative pentru viața de zi cu zi, pe care se axează această lucrare, este cel al bolii și, implicit, al sănătății. Studii anterioare care au abordat aceeași problemă, sugerează că dacă în trecut reprezentarea socială a sănătății și bolii în rândul Romilor era profund impregnată de tradiții și tipul de gândire magică atât de caracteristic acestei etnii, în prezent a suferit modificări majore. Mai exact, explicațiile științifice ale bolii au luat locul celor mistice, și încrederea în practicile de vindecare tradiționale a pierdut teren în fața procedurilor medicale. Cercetarea de față a urmărit, pe de o parte, să identifice reprezentarea socială a bolii în rândul populației Rome și, pe de altă parte, să stabilească dacă aceasta a suferit modificări importante în ultimii ani, sub presiunea reprezentărilor sociale ale sănătății și bolii în rândul populației majoritare. În urma analizei rezultatelor interviurilor realizate putem concluziona că deși multe elemente ale nucleului central al reprezentării sociale sunt menținute, cum ar fi boala privită ca pedeapsă divină, superstițiile, metodele tradiționale de vindecare sau amprentele gândirii magice, se poate constata pătrunderea unor noi elemente în limbajul curent: cauzele bolilor din registrul medical, diagnostic sau tratamente medicale. În plus, un aspect important este modalitatea în care a evoluat relația medic-pacient, în prezent fiind aproape complet eliberată de constrângerile impuse de credințele tradiționale.

Cuvinte-cheie: *boală, sănătate, Roma, tradiție, aculturație*

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ABSTRACT. In the context of the new challenges of globalization, the Roma ethnic group, internationally considered a disadvantaged minority, at the edge of subsistence, regardless of the country of residence, is permanently a topic of study in various scientific fields. One of the representative fields of everyday life on which this paper focuses is that of disease and, implicitly, that of health. Previous studies having tackled the same problematics suggest that, if in the past the social representation of health and illness among Roma people was deeply impregnated with traditions and with the type of magical thinking so characteristic of this ethnicity, at present, this social representation has undergone major changes. More exactly, scientific explanations of disease have taken the place of mystical ones, and the trust in traditional healing practices has lost ground to medical procedures and medication. The research has set out, on the one hand, to identify the social representation of disease among the Roma population and, on the other hand, to establish whether this has undergone important changes in recent years, under pressure from social representations of health and disease among the majority population. Following the analysis of the carried out interviews, we may conclude that, though many elements of the central nucleus of social representation are maintained, such as disease regarded as a divine punishment, superstitions, traditional healing methods or marks of magical thinking, one notices the penetration of new elements in everyday language: causes of diseases from the medical register, diagnoses or medical treatments. In addition, an important aspect is the way in which the doctor-patient relationship has evolved, currently being almost totally freed from constraints imposed by traditional beliefs.

Keywords: *disease, health, Roma, tradition, acculturation*

1. Introduction

In the context of the new challenges of globalization, the Roma ethnic group, internationally considered a disadvantaged minority, at the edge of subsistence, regardless of the country of residence, is permanently a topic of study in various scientific fields. From researchers in the medical field to sociologists and psychologists, everyone has been trying to sketch a portrait as complex as possible of the Roma ethnicity, one of the factors determining this interest from the scientific community being the very large difficulties faced by Roma people in the process of acculturation and, implicitly, in the integration into other majority groups. These difficulties are ascribed, on the one hand, to discrimination by majority populations and, on the other hand, to Roma people's resistance to change. This resistance to change has led researchers in the field of social psychology toward a more detailed analysis of Roma people's perceptions, attitudes and, ultimately, social representations of various representative fields of everyday

life, and of the difficulty or ease with which these change as a response to present challenges. In other words, the way in which Roma people see the world and relate to it has aroused real interest.

The theoretical framework of research

Serge Moscovici's theory of social representations underpins the theoretical model on which this research has been structured. Thus, by *social representation* we understand "a structured set of values, notions and practices related to the object, aspects or dimensions of the social environment, a socio-cognitive system permitting the survival of the individual in society, channelling behaviours and communications, as well as selecting responses to environmental stimuli" (Neculau A., Curelaru M., 2003). Scholarly literature makes reference to three main components of social representations, corresponding to the cognitive, affective and behavioural register. The cognitive component of social representations is practically the most important of the three, because without cognitions there would be no representation. Moscovici claims that social representation also plays the role of reducing the individual's psychological discomfort created by his confrontation with new things, as it transforms the unfamiliar into the familiar. Hence the affective component of social representation. The third and last component of social representation is the behavioural one. Among the functions of social representation, we note that of orienting the individual. From this perspective, the term "conditional scheme" steps into the theory of social representations; it was introduced by Flament and it entails the prescription of the way in which an individual reacts to a certain situation.

Thus, "the transformation of representations is connected to accompanying practices. A change in practices generates a modification of prescriptions, therefore, representation is under the influence of the evolution of social practices" (Neculau A., Curelaru M., 2003). The fact that a social representation is formed does not mean that its structure is definitive. As the social representation is the result of social processes, its structure is constantly evolving, it is sensitive to social modifications. The scheme proposed by Guimelli regarding changes in social representations when new practices or ideas contradict old ones entails six stages: the occurrence of the event of great impact on the group, the modification of external circumstances due to the event, the elaboration of new practices within the group and the gradual increase in their frequency, the activation of schemes prescribing the new practices, the reorganization of the representational field, the formation of a new concept and its acceptance in the central nucleus of representation (Guimelli C., 1994).

2. Material and Methods

The present study is based on a qualitative methodology which has been implemented in two Roma communities in Romania and has consisted of submitting a survey to a number of 25 subjects. The research was performed in the period March – May 2014, within two Roma communities from South-Eastern Romania. All subjects were informed about the purpose and methodology of research and voluntarily consented to participate in the research. Moreover, all subjects were assured anonymity.

The method used in the qualitative research was the semi-structured interview, based on an interview guide which sought the investigation of the following dimensions: the significance of disease, causes of diseases, methods of treatment, superstitions connected to disease and types of diseases known from one's own experience or from the experience of other community members.

The interviews lasted 20-40 minutes and were carried out in Roma people's houses. We were joined and introduced by an educator from the community school. Interview codification was performed by retaining the subject's first and last name initials, age and gender.

Interview transcriptions were followed by a qualitative analysis performed by means of a trial version of the NVivo10 software.

The limits of research: the results of this research are limited to the analysed study group and cannot be generalized to the entire Roma population, given the qualitative design, which sought mainly to gather in-depth information, substantiated by the participants.

3. Results

The social representation of disease was analysed in terms of several dimensions, mentioned above and shown below.

3.1. The significance of disease

The first of these was the significance Roma people associate with disease. The most frequent associations they make with disease are: suffering, pain, stress, punishment from God, shame, death, isolation. Of these, suffering is the most frequent association, followed by stress: 60% of respondents nominated suffering among the significances of disease and just as many associated stress with the term "disease". Moreover, we note the creation of a vicious circle, where disease generates stress, and stress aggravates the disease or becomes

the origin of new pathologies. *“Suffering, depression, hopelessness, isolation, upset, neglect by the family, family breakdown, loss of self-confidence, this is what I understand by disease” or “a state of stress, since it cannot be anything but stressful, in that you think. You submit to your thoughts more often. And it creates a state of stress and it leads to more diseases.”*

Approximately 16% of respondents consider disease shameful, an aspect also identified by other studies (Pons, 1999; Petcut et al, 2013). Shame is caused especially by the external signs of disease, and to a lesser extent or not at all by diseases which do not produce visible changes. *“When you suffer from a disease which is visible or you have something a man can see, then you are ashamed to walk. When it’s on the inside or internal, you’re not. It’s not noticed, no one knows what you suffer from. But when it’s visible, you’re really ashamed to show yourself”.*

In addition, from the interviews conducted, the idea emerges that disease is a punishment from God, an otherwise very strong faith also revealed in the dimensions connected to the causes of disease, subsequently analysed. This association was also underlined by other studies in the field (Cook et al, 2012; McKee, 1997). *I understand this by the word disease; the disease is a sort of ordeal. How can I put this, it’s a punishment from God.*

The Roma people included in the research bring up and associate disease with children. One of the possible explanations may be that, for this ethnicity, children’s health status is one of the most precarious; incidentally, it has very high rates of infant mortality, compared with the mean of the majority population (Wamsiedel, Vincze, Ionescu, 2011; Becares, 2015; Condon & Salmon, 2014; Masseria, 2010; Carrasco-Garrido, 2011, Fésüs, 2012, Ruginis, 2010).

Table 1. The words’ frequency associated with disease

Words associated with disease	Frequency in responses
suffering	60%
stress	60%
shame	16%
punishment	8%
children	20%

Thus, following the results obtained, we may assess that, for the Roma ethnic group, disease mostly signifies suffering associated with a high level of stress. We noticed the use of the term “stress”, a relatively new concept, perceived rather as belonging to medical language, an argument in favour of our hypothesis regarding the changes occurring in Roma people’s social representation of disease in recent years. However, shame and punishment are not absent as chief

associations of disease – these two significations are part of the central nucleus of the representation of disease among Roma according to previous studies, and they are still retained.

A study carried out in Spain revealed that many Roma people “perceive health as the absence of disease, and disease as a disabling phenomenon, associated with death” (Carrasco-Garrido, 2011, Fésüs, 2012). Disease only exists to the extent to which it exhibits clear symptoms endangering the ordinary course of activities or the individual’s physical existence. As soon as these symptoms disappear, the person considers himself healthy. The definition given by the *World Health Organization (WHO)*, based on the Western canon, explicitly mentions the difference in approach. For the international organization, health is “a general state of physical, mental and social wellbeing, not the mere absence of disease or infirmity”.

3.2. Types of diseases

Regarding the types of diseases familiar to Roma people, the highest frequency belongs to somatic diseases and a very low frequency to psychic ones. Most references were made to diabetes, hepatitis, renal and cardiovascular diseases. The representation of psychic diseases is very vague. Most understand by psychic disease “a disease located in the head region”, a reason why meningitis is most often considered “a psychic disease”, followed by headache, sinusitis or cancer. Among psychic disorders, however, depression, epilepsy, debility or dementia are mentioned.

Table 2. Types of disease

Type of disease	Times mentioned
Diabetes	10
Cardiovascular diseases	7
Renal diseases	13
Hepatitis	11
Depression	4
Epilepsy	3
Dementia	6

The much higher frequency of somatic diseases occurring in members of the community probably explains, to a great extent, why this type of diseases is more familiar than psychic ones. As for psychic disorders, the one mentioned most often is depression, incidentally the malady of the century in the psychiatric register, if we go by *WHO* statistics. Therefore, the frequency of the disease also guides the frequency of mentions regarding types of diseases.

3.3. Causes of diseases

Another dimension we have analysed is that of the causes attributed by Roma people to disease. The belief that God is the source of diseases becomes evident here, a belief resulting from the perception of disease as a punishment applied by Divinity for past sins. The word “God” is mentioned no fewer than 47 times in answers regarding causes of disease in the 25 interviews. *Everything is from God. What He gives... that's all. They say it was a cold and it wasn't detected, but, anyway, you know, when you are born you have Three Fates by the window. And you live according to your fate. This is from God, of course. Well, if you knew, would you still drink or eat or smoke? Disease comes from God.*

God also appears as an instrument of the curse or the evil eye, also seen as sources of diseases and suffering. *“Well, my dad cursed me for being bad. I was going to steal. I was stealing, I wasn't going home, and dad cursed me, dad was beating me, I was swearing back at him, beating him back. God created this punishment. He said: ‘God, make my son lame’, and He made me lame. If he hadn't asked this thing from God, maybe God wouldn't have made me lame.”*

These results are consistent with those communicated in scholarly literature, which suggests the interpretation of disease in the Roma community in mystical terms, as a punishment from God or as a curse. Moreover, disease is frequently associated with the feeling of shame, being a representation of spiritual and moral impurity (Dumitraş et al. 2013).

Though magical thinking is predominant in awarding causes to diseases they face, Roma people also have explanations fitting within a rather medical framework. What we found surprising here, however, was the almost unanimous opinion of cold – 31 mentions in the 25 interviews – as the source of all physical diseases faced. From a medical perspective, the following causes frequently identified were upset and stress, with 13 and 12 mentions, respectively. Nevertheless, there were Roma people who listed as causes of diseases an unhealthy lifestyle, genetic causes or poor hygiene.

Table 3. The causes of diseases

Causes of diseases	Times mentioned
God	47
Curse	8
The evil eye	3
Cold	31
Upset	25
Stress	27
Lifestyle	18
Genetic causes	6
Poor hygiene	7

Analysing answers referring to the causes of diseases, we find that, in this respect, changes in social representation take place more slowly, God still being perceived as the main cause of getting a disease, together with curses and the evil eye, these representing a durable nucleus of what we call “magical thinking”, so characteristic of the ethnic group, according to studies of the past decades (Beaudoin, 2015; Taylor, 2014). Still, we cannot ignore that explanations like genetics, lifestyle, stress, poor hygiene make their way, though to a smaller extent, to the social representation of disease.

3.4. Healing methods

In terms of healing methods Roma people turn to when confronting a disease, the results of our analysis point out a paradoxical aspect. If “magical thinking” is predominant in the image of causes of disease, the most widespread healing methods are prevalently part of the medical register. Treatments, medication, surgery – these are the main healing methods mentioned 31, 14 and 26 times, respectively. The fact that the social representation of disease is in a permanent dynamic is also proved by the identification, during our interviews, of a relatively new concept in the theory on health and disease – *positive thinking*.

“You see there are many people who, by thinking positively, get healed of some diseases. If one thinks negatively, one gets sicker.”

We also notice the acceptance of the placebo effect, based on trusting the doctor and the benefits of medication prescribed by him.

“I know, I’ve heard of a case where in a hospital there were some patients suffering from... I don’t know what disease, cancer, something incurable, and the doctor knew well that these patients would not be cured and lately had been giving them sugared water. And the patients lived for another 6 months only with the thought that the drug was good. So they thought well. They thought positively.”

Nonetheless, old cures still represent a variant of healing. But, in most cases, incantations, potions or teas are resorted to after medical treatments have not yielded the expected results or when Roma people consider they cannot follow the latter. Using coal according to certain rituals – mentioned 17 times – and the evil eye incantation – mentioned 16 times – are among the most frequent cures listed.

This is what I know, dear, why would I lie. And against the evil eye, when it hurts, you cast a spell. Even an infant this small, in diapers, takes it. I had my boy once, and Dorina cast a spell three times and spit on him and that was all, he was cured, he would’ve died in his infancy. But his niece died of the evil eye. She was too

beautiful. A man came to ask my brother to settle a wedding and he said 'begad, what a beautiful girl you have' and then my brother-in-law found her dead in her cradle. Healthy, she had nothing wrong. I have my oldest son, the prettiest child when we dress him up, and I took him in my arms and was walking down the road like that. And when I came back home, the boy was about to die, all of a sudden. He didn't have a fever, nothing... and then he gets the fever he gets it there... darn it. And that's it, he got that disease. We went to '9 Wormwoods'. He found an elderly man, I didn't know 'cause I was younger, that coal, I mixed it in a spoon, gave it to him to drink. The cure was ready; I took him to the hospital, but for no reason. We know from the elders a saying against the evil eye. I mean, when you get too much of a headache and it doesn't go away, not even with pills, not even like that, you say those words. And in most cases it pays off. I think there are a lot of Roma and Romanians who know it. There's a few words that must be said and it works against the evil eye."

Table 4. Healing methods

Healing methods	Times mentioned
Treatment	31
Medication	14
Surgery	26
Coal	17
Incantation	16

Roma people frequently associate the occurrence of diseases with bad luck, a curse or the involvement of evil spirits. Hence, according to scholarly literature, the healing methods part of a supernatural register, rather than of one based on scientific information (Singh D., 2011).

The conducted interviews also show that traditional healing methods are considered somewhat of a taboo topic. Probably, in part, because Roma people know that the methods used by them are sometimes regarded ironically, other times merely with scepticism and most times blamed by the majority population, they are reluctant to talk about them. However, from the answers received, one distinguishes a pattern specific to the use of these methods: they come as a second option after the medical one, which has priority.

3.5. Superstitions connected to disease

One last dimension in the representation of disease analysed was that of superstitions connected to disease. This is where one encounters part of the beliefs identified as sources of diseases or as cures, dreams, but also some superstitions also common among the majority Romanian population.

Table 5. Words associated with superstitions about disease

Words associated with superstitions about disease	Times mentioned
Cursed	12
God	8
The evil eye	9

“The evil eye. The only, sole superstition is the evil eye.”

“I dreamed a dream one night. It appeared I had a house in that dream, but not this house of mine that I know. It was a house and I was telling them ‘the house isn’t mine, it’s not like this in my house’, I said. Dude, and I made that house. For us, for us gypsies, or that’s what I think, I mean my family. When you dream something, it happens. And they say that these dreams of houses, so when you build a house, would be some hardship and there will be upset, and, not to exaggerate, in 2 weeks at most a 13-year-old cousin of mine died with that big accident of ours here.”

“I had this older one of a year and 10 months and that lady told my fortune in coffee grounds, she says: ‘take care with the girl, for she will get hurt, for she will shed blood’, that’s what they say, you know? ‘You will take her to statesmen, to white doctors, with white coats, like that, but fear not, it’ll be fine”. Let’s say in a week or two, three at most, the girl got hit in the eye and was torn from here to here like so, halfway. Exactly so, she shed blood, I took her to doctors, I had her stitched and I told myself I’d never get my fortune told again. It was exactly as she told me from the coffee grounds.”

4. Conclusions

The social representation of disease among the Roma ethnic group went through changes compared to the representation outlined by research conducted a few years ago. Although many elements of the central nucleus of representation are maintained, such as disease regarded as a divine punishment, superstitions, traditional healing methods, marks of magical thinking, we cannot ignore the penetration of new elements in everyday language: causes of diseases from the medical register, diagnoses or medical treatments. Additionally, an important aspect is the way in which the doctor-patient relationship has evolved to its present state of almost total freedom from the constraints imposed by traditional beliefs. One must note, however, that disease and, implicitly, death remain taboo topics in discussions with Roma people, just as references to traditional practices and beliefs are made reluctantly.

Taking into account the results obtained in the present paper, we may state that all favourable prerequisites – accurate perceptions of the facts, continually changing social representation - exist for the continuation of an education regarding health status and prevention among the Roma ethnic group.

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