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Stigma and Discrimination against Roma Patients in the Romanian Healthcare System

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Abstract

Stereotyping is a phenomenon often met in society and it is manifested by stigmatization and discrimination. This phenomenon gains a deeply negative character when it is manifested in providing healthcare to some groups of people, races, and ethnicities. This paper is based on data obtained during a qualitative research aimed to correlate the necessity of the end-of-life care of a Roma patient with Roma traditions and the existing politics and services in the Romanian healthcare system. Our research was based on 48 interviews, conducted on chronic ill persons and caregivers, in Roma communities from two regions of Romania (Cluj and Iași). During our study we found out that existing stigmatization of Roma people at the level of general society, has an important impact on the access to and quality of the

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health services. All these have a significant influence on the dignity of the Roma patients and finally represent a serious violation of human rights, in particular of the right to non-discrimination.

Keywords:

Roma patient, Romanian healthcare system, access, quality, stigmatization and discrimination

Introduction

Worldwide proclaimed since the last century, the fundamental human rights set up the basis of any political, economical, legal etc. actions and relationships, so that any legal or normative act is to be analyzed in terms of its compliance with them. These rights seem to be very easy to understand and to expose but we can often observe that the exercising of human rights (Ignătescu, 2013) in practice is many times difficult for different reasons: a mean economic interest of some powerful political structures, corruption, ignorance and last, but not least, a tendentious attitude toward certain groups of people, races, ethnicities, and nations.

Formerly a nomadic people spread throughout the world, Rroma constitute a well-known ethnic group in Romania, where in 2008, the Rroma represented 8.56% of the stable population (Brearley, 2001; CEDIMR-SE) The Romanian census of 2011 (www.insse.ro) shows that the number of those who declared themselves to be Rroma was 619,000 (representing 3.2% of the active population), showing an important difference between the figures estimated in 2008 and in 2011. One reason for this difference (Brearley, 2001; Turlic, 1996, pp. 55-60) is that many Rroma do not identify themselves with the Rroma population, preferring to adopt the language, religion and some customs of the majority population living in the area.

A 2008 study carried out in Romania indicates that the Rroma face stigma and discrimination in all spheres of the social life (Rromani CRISS). Globally, studies show that the most frequent reasons the Rroma population is dissatisfied with the healthcare services are the economic difficulties in purchasing drugs, some malfunctioning in the hospital hours and the lack of interest of healthcare providers in Rroma patients (Cemlyn et al., 2009)

Theoretical framework

Creating stereotypes is a natural function of our brain that simplifies a complex reality in order to develop further automatic responses to similar stimuli. In 1922 psychologist Walter Lippmann (1956) advanced the idea according to which all people are determined to work based on memory images and abusive generalizations. As a result, stereotypes influence the way we assimilate new information and the way we remember it. Stereotypes can sometimes be useful in social relations because the classification of individuals helps us predict their behaviour and reactions (Cernat, 2005).

Nevertheless, the tendency to predict an individual behavior in relation to the Rroma can often lead to serious consequences like acts of direct discrimination and violation of their rights.

According to some authors, the stereotyping of the Rroma has multiple causes. In contrast with the populations met in their places of exile, the Rroma have a nomadic lifestyle and a natural tendency "to run", to accept marginalization and their low social status. The temporary homes during the journeys of the Rroma were always isolated on outskirts of towns or villages. This way the difference between the Rroma and the local population came into existence and it gradually became a social reality. The perception of the general population of the Rroma is usually a negative one, because they are strangers in the places they come to and their customs and beliefs are different from those of the people they come in contact with. Over time, the Rroma were hunted, deported and punished. In this context it is relevant to mention the Gypsies' slavery phenomenon in the 13th and 14th centuries in Romania. All these features contribute to the perpetuation of negative images about the Rroma (Brearley, 2001; Surdu, 2010)

An aversive or hostile attitude towards a person just because they belong to a particular group and is believed to have intolerable features of the group is defined by G. Allport (1954) as *an ethnic stereotype*, i.e. an antipathy based on an incorrect and inflexible generalization.

Thus, the phenomenon of the so-called "marginal social groups" appears. In order to exist it permanently needs a system of values and norms prevailing through a direct exercise of power or dominion and through a set of values and norms that are established or usurped. According to the dominant axiological system, the status of marginal groups is low precisely to its definition as *marginal group* (Wiehn, 1996).

Relevant studies in the field show that all social inequalities, and therefore those of the marginal groups are and remain phenomena of power and domination (Thomas, 1992)

The creation of stereotypes in a society becomes dangerous especially when it leads to prejudices, determined by stigmatization which represents a very strong social labeling (Bourhis, Gagnon, Mod'se, 1996)

Stigma associated with ethnicity is usually based on excessive social anxiety. There are situations when people of a certain ethnicity are judged based on assumptions that refer to their moral integrity. Thus, all the people who share one characteristic, the whole ethnicity, respectively, are assigned negative social features such as: the desire to steal and not to work, being a danger to others etc.

In this article, the authors analyze the way social stereotypes and stigma against the Roma lead to violation of their fundamental human rights and affect their dignity in the context of healthcare services.

Methodology

The goal of this research was to determine the factors (social, economic, medical, cultural etc.) which could influence on the dignity of Roma suffering from advanced chronic diseases.

The phenomenological type of individual semi-structured interviews with Roma suffering from with serious chronic diseases and caregivers, were conducted in order to thoroughly analyze the knowledge, attitudes, behaviors, beliefs and values in Roma community in situations of confrontation with chronic incurable diseases. We interviewed persons suffering from oncologic diseases in advanced stages, people with incurable complications of diabetes, stroke, and psoriasis and persons who took care of such patients at the moment or had taken care of them in the recent past.

We conducted 48 interviews in Roma communities in two Romanian counties – Cluj (25) and Iași (23) . The interviews were audio recorded and transcribed into Romanian language, and some of the interviews made in Cluj County were translated from Hungarian. The data collected were coded and subsequently analyzed thematically.

Because the Roma population is identified as an extrinsic vulnerable group due to their low socio-economic status, their minority status and the social stigma they are facing, we took into consideration

that interviews could lead to a further developing of the sense of stigma and frustration. For this reason, the access of the researchers into the Rroma communities was facilitated either by community leaders (*bulibasi*) or by the persons who were trusted in the community, i.e. general practitioners and health mediators. A simple, non-discriminatory and non-stigmatized vocabulary was used for asking the questions.

The study was approved by Research Ethics Commission of the „Grigore T.Popa” University of Medicine and Pharmacy of Iasi, Romania.

Limitations of the study

Our study was limited by both methodology and setting.

Because of the qualitative methodology which was applied the results have limited direct generalization.

Another limitation of this study arises from the fact that the interviewed participants were recommended by the leaders or the general practitioners in the communities. For this reason we can only speculate about the Rroma who were not recommended or who refused to participate.

Also, age-related experience has not been fully examined in this study and therefore this variable should be included in a future research. In addition, future investigations should include the perspective of physicians involved in care of Rroma patients.

Participants

The participants in our study belong to various Rroma communities identified according to the traditional crafts they practice: Kalderash/bucket-makers (*caldarari*), bear handlers (*ursari*), boyish/miners (*rudari*), spoon-makers (*lingurari*), fiddlers (*lăutari*), etc.

We conducted the interviews in two regions of the country, i.e. Iași and Cluj. In Iași we had access mostly to ”closed” or traditional Rroma communities while in Cluj the Rroma communities approached have a higher degree of acculturation, the Hungarian Rroma being more integrated into the culture of the general Romanian population. The structure of the study group is presented in Table 1.

Table 1. Number of survey participants according to caste and gender

Caste	Total participants	Female	Male
Close-culture castes in Iași county: bucket-makers, spoon-makers, miners, bear handlers, fiddlers	16	6	10
Acculturated RRroma in Iasi county	7	5	2
Hungarian RRroma in Cluj county	25	15	10

The participants in our study formed a heterogeneous group in terms of age, gender, education and income, allowing us to gain as much diversity of experience and opinion as possible. The average age was 58 (ranging from 21 to 78); the levels of education ranged from “no education whatsoever” to vocational school. The distribution according to gender showed a slightly higher prevalence of females (26 women and 22 men).

Results and discussions

Our study showed that many participants consider that stigmatization and stereotyping are among the leading factors that injure their dignity.

Limited access to the healthcare services

During our study we found out that the Rroma often use the emergency medical care, this fact being determined on the one hand by the low rate of health insurance among the Rroma and on the other hand because many of the Rroma seek for medical assistance just in case the disease becomes serious and unbearable as in many Rroma communities a disease is considered to be a shame and hidden as much as possible.

Many of the interviewees noticed a discriminatory attitude of the medical staff when they used the emergency care services. The Rroma complaints refer both to the quality of the provided services and to the access granted to medical services that differ from those provided to the general population. *“When a Gypsy comes doctors are more reserved but when a*

Romanian comes they practically bug him! Big difference!” (SI.2-i24am3-ur) tells us a 71-year-old bear handler Rroma.

A particular case of discrimination in the healthcare system is related by a Bădănar Rroma man: *”Yes, when I went to the emergency with my dad, a Romanian who smelled badly from a distance came later; he was so filthy that you got sick if you touched him. They left my father lying on a bed and examined the Romanian patient; he spent there almost an hour and a half... nobody wanted to see him! ... How did they examine the hobo/ bum, and not my father who was clean? Just for being a Gypsy?!” (SI.2-i22am1-bd)*

The doctors’ indifference was also pointed out by a 52- years-old Kaldarash male Rroma who told us how he felt discriminated when he called the emergency medical service: *”And he kept me outside till 3 o’clock , with broken legs, after I had fought with a Gypsy. And he didn’t want to see me... And he saw me suffering, yes he did !” (SI.2-i2am2-cl).*

Some Rroma told us about situations when their access to medical services was limited or denied because of a stigmatizing attitude of the medical staff. A woman from the Kaldarash community informed us that they are always refused when they call the emergency number: *”The ambulance doesn’t come to us. I have a sister-in-law here, it’s hard... very hard... she had a stroke and one hand was paralyzed, she was full of sorrow. The emergency/ ambulance never came here when she called it... and she is a diabetic too, she has many diseases. Old people... They say that Gypsies beat them and throw stones at them! ...But it was 40 years ago! Gypsies got civilized now. ...We are happy when the ambulance comes to save a person.” (SI.2-i5af2-cl)*

Negative generalization

Generalization is mentioned and assessed by the interviewed Rroma as a phenomenon that offends and violates the dignity of the Rroma ethnicity. One of the most important prejudices to the Rroma is the negative labeling of the whole ethnic group (for example *”Rroma are thieves, so people have to stay away from them”*), which shows that at cognitive level there is an intolerable generalization with all its negative consequences: lack of respect towards the personality and individuality of each person, labeling and discrimination. This manifestation, according to Goffman, is a *tribal stigma*, is hereditary transmitted via race, nation and religion (Goffman, 1963). The tribal stigma is very hard and almost impossible to remove because it has visible features (skin color, facial features etc.).

Social labeling essentially changes attitude of others towards a stigmatized person (or a group); it has a great influence both on the person's (or the group's) attitude towards themselves and also to the environment. Some study participants complained to us that they felt a specific labeling when they interacted with medical institutions.

Fighting against the existing stereotypes

In many interviews we found that Rroma face the phenomenon of stereotyping that is often clearly manifested in their relationship with the general population. They acknowledge that they understand the source of these misconceptions, but they would like the attitude towards them to be changed as much as the life and behavior of the Rroma have changed in recent decades. A *bulibasa* of a bucket-maker community tells us about the Rroma history and their migratory life, but mentions that today things have changed: *"No, we don't hold our heads high! Let's not forget who we were and where we came from! We were dirty, lived in tents ...full of sorrow; now ... everyone lives modestly, lives his own way, a clean life, washed and cleaned, with cars around us, TV sets, telephones...just admire! God, who we were and what we got!"* (SI.2-i6am2-cl)

Interviewees admit that even if things have changed in general, many of them continue to experience the existing stereotypes in society and suffer from stigma and discrimination, including in relation to the medical system. We had a very informative discussion on this topic with an acculturated Rroma woman who completed 12 years of schooling and worked among Romanians in different environments. She revealed to us that she did not feel respected when she mentioned her ethnicity both in hospitals and in everyday life. It is a permanent struggle for her to prove that she does not correspond to the stereotypes rooted in society: *"Why do they stick my ethnicity on my face like a label? They see my dark complexion and define me, just from the beginning, sticking logo on my neck: "You are a Gypsy; sit and wait for your turn; let them die, they are too many anyway. [...] And I try to speak calmly, to explain, but when I see that it is impossible, I go on, I complain to the manager, I find the person to understand and help me..."* (SI.2-i18af1-rr)

Trying to avoid the cultural stigma they have to face, the Rroma told to us that many times they hide their ethnicity or even deny it. Being asked what *respect* means to him, a man of the spoon-makers Rroma caste briefly told us: *"I don't want to be called Gypsy!"* (SI.2-i10pf2-lg). This desire is motivated by some people's frustration about the cultural differences

of their ethnic group, differences that are sometimes difficult to accept by the general population.

Aware that some representatives of their ethnicity do things that are not entirely accepted by the general population, some of the Rroma participants explain this fact saying that these are "the others" within their ethnic group; this way they establish an internal classification (within their ethnic group) in "good" and "bad", using the behavioral standards of the majority. From the discussions with Rroma people from different castes we noticed that many of those interviewed stated that they were victims of a general stigmatization, when called "Gypsies"; they consider the differences within their ethnicity to be essential. This explanation was offered us by an acculturated Rroma man: *"Yes, there are many groups. We are Romanized (acculturated) Gypsies... There are also greengrocers, bucket makers...there are other nations and **we cannot compare ourselves to them!** We are like you! But according to the tradition, the bucket-makers are the original Gypsies. Those with skirts are original Gypsies. They keep tradition... **They are different from us!** The language is not the same. Just a few, 5-10%, speak **louder and faster and more confusing.**"* (SI.2-i17am1-rr)

We observe that people who decided to stand out from the ethnic group they belong to, try to find differences in small things, such as the accent, speaking speed, clothing style etc., striving to convince us or to convince themselves that they are **different**.

In many interviews we were told that as long as they did not mention that they belonged to the Rroma population the attitude of the medical staff was adequate and it changed when they made their ethnicity public. A sick woman from the spoon-makers Rroma community told us she did not mention her ethnicity and did not feel discriminated when hospitalized: *"Well, they couldn't tell...I refrained from saying it, because there were many women and they keep distance from the Gypsies ...and I didn't say it either ... Yes, if I had said it, I think they would have behaved differently...Yes, I know there was a gypsy woman with gypsy accent and I talked to her when we were alone..."* (SI.2-i11pf2-lg)

A 72-year-old Rroma woman, from the bear handlers' caste told us she was very well treated by doctors and by her ward neighbors in a hospital. While discussing with us she admitted that the medical staff could have changed their behavior if they knew she was a Gypsy: *"We were seven women in the ward. If they had known I am a Gypsy... But do you think I told them I am a Gypsy? ...And even if I had told them this I wouldn't have been*

ashamed!" (SI.2-i24am3-ur). Even if that woman proudly declared to us that she was not ashamed of her ethnicity we took into account that she hesitated to mention it in the hospital in order to avoid potential misunderstandings.

Many of the participants confirm that some of the Rroma ignoring the rules of personal hygiene determines the general population to marginalize and stigmatize the Rroma in general. In a conversation about the cultural differences between Rroma and general population with a 63-year-old woman who belongs to an acculturated Rroma community, she admitted that some of the Rroma had a specific behavior, they were impulsive and noisy, but she mentioned that all representatives of their ethnicity are stigmatized because of them, and that is not right/ fair:" *If something happens, some of the Rroma start to "break the doctor's neck", to curse and to speak badly of the doctor and all of us suffer because one or two Rroma!"* (SI.2-i14pf2-rr)

Mechanisms of protection, self-isolation from the general group

Literature states that one of the mechanisms of protection of the group/ person affected by stigma is isolation or self-separation from the general group (Turliuc, 1996; Bourhis, Gagnon, Mod'se,1996). From the interviews conducted in closed communities that keep and respect traditional cultural norms (for example: bucket-makers from the region of Iasi), we remarked that a self-isolation trend leads to self-stigmatization and it highlights more cultural differences in relations with the general population. The *bulibaşa* of a Kaldarash community told us that he tried to find money to build a medical institution just for the Rroma, even a kindergarten for the RRroma children only: "... *And then I asked for approval to build a hospital here. I talked with the manager to give us some space to make a project plan with the European Union and to build a hospital for children, a maternity home...*" (SI.2-i5af2-cl)

Being strongly influenced by the culture and by the respected values in the community they belong to, and at the same time being dominated by the fear of being stigmatized and discriminated for keeping their own traditions, some of the leaders of the Rroma communities prefer to isolate their community members even more from the general population. The data from the literature treating the subject show that due to their history of persecution, the elderly Rroma

still believe the fewer non-Rroma know about their language and traditions the less they will be influenced (www.coe.ro; Zamfir, E. & Zamfir, C. 1993)

The thought of being discriminated against is not unusual for a Rroma, was a common attitude of many respondents. This could mean, on one hand, a low trust in institutions entitled to intervene and solve such cases and a high level of ignorance of such bodies/ systems, but on the other hand, it can mean a high level of acceptance of stigmatization. At the same time accepting stigma proves that the discriminatory situation tends to become natural, as we noted from the views of some of the interviewed persons.

Mechanisms of protection, noisy conflicts

Being involved in different situations of discrimination or stigmatization caused by the medical staff, the Rroma are looking for various solutions. Some of them initiate noisy conflicts involving mass media, public representatives and community leaders. A 42-year-old woman from the Kaldarash caste, daughter of a chronically sick person, described angrily how she asked the support of the journalists and invited television when she felt discriminated in a medical institution. The woman told us that she called the emergency medical assistance for her sick mother but she faced doctors' indifference. After generating this conflict in which doctors with authority were involved, the sick woman was hospitalized: *"Madam, my mother has a high blood pressure! ...Look at her hand! She (the doctor) says: "Would you, Gypsies, ever wait for your turn and stand there in a line? Get out! Guards!" Well, I want the guards and a camera also, I said. I went to the hospital manager and I made a complaint."* (SI.2-i9af1-cl)

Mechanisms of protection, avoiding discriminatory attitude

Other Rroma may choose more peaceful ways of behavior such as looking for doctors that would provide them a proper medical assistance and avoiding the institution where they met a discriminatory attitude.

A Rroma woman, chronically sick for a long time, told us how she deals with a discriminatory or a stigmatizing attitude when she is provided medical or other services: *„It happened to me, and not just at the doctor! It happened to me to be marginalized just because I am darker. But I didn't pay attention to it... I addressed the others and the problem got solved. I have an*

optimistic nature. If you don't pay attention to me I will find other doctors and other medical services..." (SI.2-i18af1-rr)

Mechanisms of protection, tendency to detach from their ethnic group

Some Roma told us that they tried to prove they were different and deserved to be respected, this way being compelled to discuss it with doctors who treated them. This is a tendency to detach from their cultural group and to demonstrate they are not one of the "bad" ones. An acculturated Roma woman told us that before going to a doctor she assured him/her she would not cause any problems. As a result the woman told us she was very pleased with the services she was provided: *"Before talking to me, they put me in the same boat with all RRroma... But after a short discussion, maybe it's just my feeling, I was given more attention..."* (SI.2-i14pf2-rr)

If we were to compare approaches (Roma vs majority population), we found in our study cases in which doctors treated the Roma differently and discriminated them. Many study participants said that they frequently confronted situations in which the doctors behaved differently with patients depending on their ethnicity, making the Roma feel humiliated and discriminated. Nevertheless, in many cases respondents said they had a good relationship with their family physician who they trusted and respected a lot.

Acculturation impact

If we compare the two regions where we carried out our research we can assert that in the interviews in the Roma communities from Cluj county, the phenomenon of discrimination in medical institutions is less told about. Many of the interviewees told us that they were satisfied that both the medical staff and patients from the same department treated them adequately. These data differ from those of Iasi county, where we have been told about obvious cases of discrimination, maybe motivated by the fact that the Roma in Cluj have a higher degree of acculturation, they are more integrated into the culture of the general population, and do not strictly follow behavioral and clothing traditions.

Conclusions

The unfair and unjustified treatment of persons of a particular ethnic group leads to discrimination against them, which has a strong social, economic and political impact. The negative attitude of the society and professionals in the healthcare system, as we noticed in the interviews, is expressed in various ways. Labeling people by means of a demeaning and offending language (insults, mockery, and reproaches) is something the participants in our study noted. Overall, the stigma related to ethnicity merely exacerbates the inequalities existing in society in general and the ones existing in the healthcare system in particular. The latter is manifested more frequently in: limiting the access of the Rroma to health services, poor quality and the inadequacy of the required medical service, indifference and brutality in the behavior of professionals in the healthcare system etc. All these have a significant impact on the dignity of the Rroma patients and finally constitute a serious violation of fundamental human rights, in particular the right to non-discrimination (McGarry, 2012).

Being aware of the stigmatizing attitude of the general population, the Rroma from the castes tend to keep their culture and traditions closed, making a clear separation from the general population; this tendency reaches a point where they desire to have separate schools and hospitals. The research done in the field shown that segregation has profound negative effects on the phenomenon of ethnic integration into the general population, especially in relation to education, economy, employment and public health (Williams, 1999).

Stigma undermines the society's ability to take constructive measures and it contributes to the occurrence of distorted views, which obstruct the objective of making decisions, thus leading to discrimination and personal tragedies. In order to overcome discrimination and ignorance in the Romanian society we gradually need to shape a humane and lucid attitude towards various problems of the Rroma people, without discriminatory attitude and prejudices, especially in the healthcare system. This process involves the promotion of the universal human values, of the fundamental rights and freedoms among professionals in the healthcare system, who must become familiar with the cultural particularities of the Rroma population, as to respect its autonomy and cultural identity. Establishing an effective intercultural dialogue will ultimately lead to the respect of dignity of Rroma patients;

this dialogue is also meant to avoid worsening the already vulnerable condition due to their belonging to an ethnic minority.

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