Postmodern Openings

ISSN: 2068 – 0236 (print), ISSN: 2069 – 9387 (electronic)

Coverd in: Index Copernicus, Ideas RePeC, EconPapers, Socionet, Ulrich Pro Quest, Cabbel, SSRN, Appreciative Inquery Commons, Journalseek, Scipio, CEEOL, EBSCO

Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context

Rodica GRAMMA,
Andrada PÂRVU,
Angela ENACHE,
Gabriel ROMAN,
Silvia DUMITRAŞ,
Beatrice IOAN

Postmodern Openings, 2013, Volume 4, Issue 1, March, pp: 117-139

The online version of this article can be found at:

http://postmodernopenings.com

Published by:

Lumen Publishing House

On behalf of:

Lumen Research Center in Social and Humanistic Sciences

Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context

Rodica GRAMMA[1], Andrada PÂRVU[2], Angela ENACHE[3], Gabriel ROMAN[4], Silvia DUMITRAŞ[5], Beatrice IOAN[6]

Abstract

Morbid states are determined by complex factors acting in a synergistic system. Thus, population health is an integrated indicator of social development of a country, reflecting the socio-economic and moral welfare of the people, living conditions and consumption of health services, as well as the level of adequate education about risk factors and healthy behaviors. For these reasons, we decided to analyze the role of the person and of the health system for public health prosperity, given the responsibility assumed by each party, highlighting the specific cultural context of Romania. Based on the results of a qualitative study conducted on two groups of patients in the terminal stages of the disease in the general and in Rroma populations, some frequent perceptions of their own health and the role of the health system have been described.

[1] Postdoctoral researcher, Center for Ethics and Health Policy, University of Medicine and Pharmacy "Gr.T.Popa", Iaşi, Romania, e-mail: rodicagramma@yahoo.com
[2] Postdoctoral researcher, Center for Ethics and Health Policy, University of Medicine and Pharmacy "Gr.T.Popa", Iaşi, Romania; Assistent Professor, Hematology Department, "Iuliu Hatieganu" University of Medicine and Pharmacy, Cluj-Napoca, Romania
[3] Postdoctoral researcher, Center for Ethics and Health Policy, University of Medicine and Pharmacy "Gr.T.Popa", Iaşi, Romania
[4] Postdoctoral researcher, Center for Ethics and Health Policy, University of Medicine and Pharmacy "Gr.T.Popa", Iaşi, Romania
[5] Postdoctoral researcher, Center for Ethics and Health Policy, University of Medicine and Pharmacy "Gr.T.Popa", Iaşi, Romania
[6] Associate Professor, Research Coordinator, University of Medicine and Pharmacy Gr.T.Popa", Iaşi, Romania

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

Keywords*: health perception, individual responsability for health, social responsability, determinants of morbidity.*

Introduction

Degree of population illness in a community is the result of the action of several objective and subjective factors, of macro and micro scale, generically called "determinants of morbidity". These include economic and social development, which determines a certain standard of living for the individual, the inherited genetic material, specific environmental factors, adopted lifestyles, often unhealthy, eating habits, poor offer of medical services, but not rarely, the insufficient consumption of such services, which, in a cumulative manner, are leading to increased morbidity and further of mortality rates. As it is mentioned in the results of several authors researches, the cultural features, faith and values promoted within a society is an important factor in determining the health status of a population.

Eckersley (2007) considers that cultural influences are the most important social determinants of health and wellbeing, observing how cultural expression, or translation, of the spiritual, especially through religions, can affect health.

Mc Laughlin & Braun (1998) suggested that "the health care practitioners must learn about the perspectives and values of a variety of cultural groups and how these cultural values intersect with those of the dominant culture, especially in the health care arena" (p.116).

It is obvious that health is the value underlying establishing priorities in all health systems. At the same time, the perception of illness at the individual level is strongly influenced by certain customs, values and beliefs that differ from one culture to another.

Within a research conducted in order to identify bio-psycho-socio-cultural factors that have an impact on the dignity of dying patients, specific aspects of perception of health and illness by participants in the study have been highlighted.

The results of this study reflected the specific psychosocial and cultural features of some groups of terminally ill patients in two Romanian regions. However, given that one of the ethnic groups with an important weight in Romanian population are Rroma, we have

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

developed a separate sub-study to determine the existence of specific cultural features of this ethnic group related to health and disease. This study highlighted the nature and magnitude of problems of terminal patients, accessibility, acceptability and quality of offered health services from the point of view of the patient at the end of his life.

Methodology of study

In this article the results of a qualitative study conducted on two groups of participants from the general population and Rroma from two Romanian regions, counties of Cluj and Iasi, will be discussed. The study included 48 patients from the general population and 48 Rroma patients at the end-stage of disease. The tool of investigation was *individual semi-structured interview*.

Since Rroma are divided into certain castes, according to their previous occupations (bucket-makers, spoon-makers, boyish, bear handlers, fiddlers etc.) and to understand more deeply the cultural specificity of this ethnicity, we conducted interviews in different communities with representatives of various castes in two regions of the country included in the survey.

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 characteristics of the Rroma participants group

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

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

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

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).

The characteristics of the participants group from general population

Table 2. Number of survey participants according to region and gender

Region	Total participants	Female	Male
Patients from Iaşi county	24	7	17
Patients from Cluj county	24	11	13

The average age was 58 (ranging from 18 to 87); the levels of education ranged from „pramary school" (11 persons), „high school" (3 persons), „vocational school" (25 persons) to „high education" (9 persons). The distribution according to gender showed a prevalence of males (18 women and 30 men). In the study participated representatives of different confessions: orthodox (33 persons), other confessions (11 persons).

All interviews were audio recorded and transcribed. The data were coded; the code contains information on the number of study, age group, sex, region and caste membership (in Rroma patients).

Participation in the study was voluntary, without imposing constraints or rewards. Participants signed informed consent form before applying to them the research tool. Respondents were guaranteed the right to withdraw at any time during the discussion.

Access of the research team in Rroma communities was facilitated by community leaders (bulibash), or people trusted in the community (eg. doctors, health workers and etc.). Interviews with Rroma patients were carried out in communities to reduce the risk of psychological distress and sense of vulnerability of those interviewed. In formulating questions was used simple, non-discriminatory and non-stigmatizing vocabulary, avoiding potentially offensive words or phrases.

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

Respondents were informed that they could choose not to answer questions which they considered awkward.

Patients in the general population were interviewed during their hospitalization.

The study was approved by the Research Ethics Committee of the University of Medicine and Pharmacy "Grigore T. Popa", Iasi, Romania, under which this research was conducted.

Results and discussions

Lifestyle plays a major role in most of the illnesses in industrialized societies. The World Health Organization Report (2002) identified the top ten factors contributing to the global burden of disease six of which are related to lifestyle: unsafe sex, high blood pressure, tobacco use, alcohol use, high cholesterol and obesity.

Even though participants often perceive illness as a punishment from God and associate it with mystical phenomena, they do not exclude elementary logic, being aware and sensing real risk factors that have caused illness.

In conversation with a woman from coppersmith caste we note that, on the one hand, she explains the disease as a result of lack of faith in God, and on the other hand talks about the importance of healthy eating and clean water. Being asked why people get ill, she answered:

> *From the faith in God ... that's why everyone is so sick ... from water, from food that is poisoned from another countries and it is not good, as it was before* ...**SI.2-i5af2-cl**

Food factor is also mentioned by a Rroma woman aged 64, with elementary education level (6 years at school):

> *People get sick from the food ... one day goes by, other one, and you hear that someone is sick ... he has one disease, or other disease... where does it came from? The food! It's with chemicals, it's with this, it's with that ... even those apples on the tree are infected* ... **SI.2-i16pf2-rr**

The interviewees believe that in other European countries longevity and life expectancy is much higher compared to Romania and the factors they consider responsible for this situation are sedentary life,

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

alcohol and stress. A 38-years-old man, with 4 years of primary school tells us about illnesses:

> *From grief, from food ... I've seen abroad 90 years old to ride a bike! In our country 60 years old people are sick, one stay in bed when he is 60! From alcohol, from grief…* **SI.2-i22am1-bd**

A number of health risk factors are mentioned by a 52-years-old man without any school studies:

> *So many people get sick with grief and anger, the stress ...* **SI.2-i2am2-cl**

An intuitive explanation of diabetes suggests a woman of 59 years, without education: "*From this grief... from a lot of crying ...*" (SI.2-i23pf2-cj).

A cancer patient, 65-years-old, believes that financial problems and ongoing life stress had caused his current condition:

> *After 42 years of work I have a 900 Lei pension ... with moral commitment ... I had 2 weddings and 10 funerals this year! Well, to handle all that.... Perhaps in terms of stress I was blocked* **SI.3-7m2is**

We have met other rational explanations for diseases, such as hereditary background or congenital problems. A 64-years-old Rroma woman with 4 primary classes explained about diabetes, intuiting the genetic causes of the disease:

> *Perhaps it is a hereditary disease, because her mother also had diabetes.* **SI.2-i14pf2 -rr**

Or, as explained the cause of his illness a man of 33 years who suffer from epilepsy since birth, with a severe physical disability: *Because my mother has high blood pressure.* **SI.2-i42pm1-cj**

Most of those interviewed from both groups considered that harmful working conditions are the main triggers of the disease. A man of 68 years, with elementary education, explained the illness of his wife:

> *Because of the place where she worked, at C., in that misery, in that dust...* **SI.2-i30am2-cj**

A 81-years-old woman, without education, in a simplistic way gives explanation of various illnesses, *I have asthma, heart problems ... My heart glands are staffed with dust. Cause I worked sweeping. Now this dust is here.* **SI.2-i32af3-cj**

Some participants found the explanation of their illness in aggressive, incorrect drug treatments received in the past. A 40-years-old woman with uterine cancer told us:

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

... either in hospital in intensive care when doing vaginal lavages, or that I took injectable contraceptives or have done much in a few months. ... And I think that because of this I could have it, that the body was sensitive and it started ... **SI.3-10f1is**

One of the participants, a man of 75 years, with rectal cancer, believes that part of guilt in aggravation of his disease has the doctor who treated him with indifference and mistrust in the early stages. Even if the patient admits that much of the blame for illness he bears himself due to his unhealthy behavior, however, he wished to be heard by the doctor, who refused assistance, considering him healthy, which upset him very much.

... It was also my fault, I've smoked a lot, living conditions are not very good ... and then arthritis in 1993. The doctor used to tell me when I was coming for a prescription, Go away, and don't teach me medicine! I saw you coming at me ... as a tree, so tall ... you simulate! Run ... sir, away! **SI.3-17m3is**

Although many of those interviewed properly and adequately explained the reasons causing the disease, we have noticed that before the diagnosis is established, it is frequently met an indifferent attitude or luck of actions in applying preventive, prophylactic or early health control measures. This attitude leads eventually to late detection of the disease. A 56-years-old Rroma patient, with operated prostate cancer, recalls how he reacted when he started to feel sick:

It took seven to eight months and I still haven't gone ... I still haven't gone, I did not know ... maybe it gets better, maybe I can heal, whatever, but at a time it was serious! And I was working at someone and there I fell down ... I didn't know and they took me from there to the hospital..." (SI.2-i37pm2-cj).

This patient's wife remembers the period when her husband struggled in pain without going to a doctor," *Well because he said that it hurts, it hurts, but he didn't say what he had, only that it hurts, that it hurts, he was complaining. And then I said, why don't you go to a doctor for him to see what it is? And so my brother went on ...* **SI.2-i38af2-cj**

A Rroma patient with colon cancer remembers that he went to the doctor only after a long period of suffering, when it became very serious.

And at home I could not go to the toilet ... a year ... one year ... A family doctor came and saw me and then came the ambulance ... **SI.2-i45pm2-cj**

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

The same attitude is also encountered in a man of 65 years, diagnosed with colon-rectal malignant tumor.

> *I was feeling tiredness, I was feeling not like me, but was primarily it was tiredness. ... I did not come when it got worse. At first I did not realize, I thought that was because of work ... I came to the Emergency and they checked me and found me not so good.* **SI.3-15m2is**

From the stories of many people included in the study from the general population, we can see clearly that the diagnosis of cancer is established for the first time when the disease is already in an advanced form. Cancer is diagnosed in emergency cases or is discovered accidentally, being suspected an aggravation of an old disease. A 70-year-old man recalls how he was diagnosed with gastric cancer, he being convinced this is an aggravation of the duodenal ulcer of which he has been suffering for 15 years:

> *After 3-4 day I was asked to do a CT and there it appeared I had cancer…on September 7th I had been admitted to hospital and on the 14th they cut and sewed me…metastasis.* **SI.3-12m3is**

Given the well-documented relationship between lifestyle, disease burden and healthcare costs, it makes economic and medical sense to hold individuals morally responsible for their health-related choices and actions. We are still looking for answers to the question why when their health gets worse, without any reason, these people don't seek medical assistance right away? What is the cause that lets the cancer in patients to be detected only at a very advanced stage? From the carried out interviews we can determine several hypotheses that could provide an explanation towards this serious issue from the public health system.

Peculiarities in defining the state of being healthy and ill

It is pointless to start a discussion about the culture of health without taking into account the environment, values and traditions which represent the base of every person's education in a society. Culture is a very complex phenomenon and it includes dozens of definitions. When analyzing them we can observe that culture is determined by thinking, feeling and actions patterns characteristic for a population or society, with a subsequent manifestation of those patterns into precise things. Within the ample term *culture* there are included those

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

systems of values which under the influence of different factors (and often some ideologies) have been accepted throughout history and were rooted as behavioral norms in a human community (Georgiu, 2001, p.9-11). This influence is observed on the perception of the state of being healthy and ill from our study.

Most of our respondents defined health as the absence of disease. This unique vision on health and illness leads us to the fact that health becomes a concern only in the presence of some dramatic symptoms or incapacitating consequences, thus the concept of prevention is almost nonexistent, although as previously mentioned, patients are aware of the risk factors and the conditions of a serious disease occurrence. In these situations, they go to the doctor only in the advanced stages of the disease, when the symptoms are obvious.

Based on that belief, in discussions with Rroma participants we observe a peculiarity of the attitude towards the payments for healthcare insurance. Some of the Rroma included in the study explain us that it is right to pay only for the services that are used immediately, fact that excludes the possibility of any payments for prophylactic services. The wife of a diabetic patient, a 67-year-old Rroma woman is astonished by the fact that a permanent contribution needs to be paid, no matter how small it is (16 lei) even when you are not ill. „ *And if I am not ill, why should I pay? Does this mean that I need to pay for the whole year?*" (SI.2-i21pm2-bd) The medical assistance is perceived as the one that treats the symptoms while the importance of the preventive aspect is not understood. Thus, based on the Rroma concept regarding the direct relationship between disease and death, only when the person manifests the state of illness, the measures must be taken immediately and peremptory. This conviction determines the Rroma people to become active consumers of the emergency services and be indifferent to preventive measures.

A young Rroma woman aged 28, tells us in the same context that she doesn't use the medical services as long as nothing is wrong, even though she understands that she could have a disease (she tells us about her bulgy lymph glands). She thinks it is natural to go to the doctor only when the disturbing factor appears which could be solved immediately by the emergency assistance.

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

Anyway I am ill, but I don't go to the doctor…I don't go, because I am afraid! After giving birth, some big nodules appeared in my head. I have them for a long time, for about 9 years. And since then I live this way. And I'm not going to any doctor! ...It doesn't disturb me! If it were something more serious that disturbed me…I would go, normally, to the doctor, to hospital, to the emergency. That's the place where we run to, to the emergency! **SI.2-i34af1-cj**

A 31-year-old woman told us that she saw the doctor only when she had given birth. That was when she was diagnosed with ovarian cyst and the doctors recommended surgery for her. However, the woman didn't see the necessity of that surgery, thus ignoring the situation described by the doctors.

*I haven't seen any doctor since giving birth…No, because they told me I had a cyst and I got scared and I decided not to go…***SI.2-i29af1-cj**

From the discussion with this woman, we can observe that she identifies the doctors with those who give the bad news, a fact that induces fear and unwillingness to communicate with the medical staff. The avoidance of the discussion and the thought of illness leave the false impression of the disease absence.

We encountered a situation where the patient told us that she easily revealed to others the diagnosis she was given just because she didn't fully understand how serious it was. Only when she saw the worry and fear of those who found out about her illness, the patient started to have a much more responsible attitude towards her treatment and illness.

*I wasn't afraid to tell them, but somebody told me that I was too unconscious. I told him, during a conversation, that I had cervical cancer and he told me, Hey, you're saying it with such an ease, probably you're just too unconscious!...Well, I was surprised! Why did he tell me that I was too unconscious of the disease? Perhaps how I understand him, because I didn't know what tough disease it was.***SI.3-10f1is**

A 57-year-old man from the general population, a cancer patient, admits the wrong attitude of the population towards their own health. Based on his own experience, he thinks that a specific characteristic for our nation is that the medical services are accessed by the ill people only when the suffering becomes unbearable.

…Our people are negligent; they don't see the doctor not even in 10 years. If I had gone to the doctor when it hurt me, then I wouldn't have been in this

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

*situation. Maybe if I had gotten the surgery, it would have been differently…Now I'm suffering more…But our problem is that our people go to the doctor only when it hurts them and if it doesn't hurt them, then they don't go to the doctor for a long time. If he injures his leg, he just bandages it. If he cuts his hand, he just applies a compress…you won't see him going to the doctor…You will hear him telling you that he has no money…***SI.3-20m2is**

From both research groups, many interviewees confirm that they began to think more about the importance of visiting the doctor after they were given a serious diagnosis. A 53-year-old Rroma woman, the wife of a serious chronic patients tells us that she regularly pays visits to the doctor for receiving the consultations of the family doctor, for both her and her husband, *I got to see the family doctor for me too...if not for me, then for my husband…I have been to the doctor 2-3 times this year…* **SI.2-i28af2-cj**

A 63-year-old Rroma man with a severe heart disease tells us that he is a frequent patient who sees the doctor and also strictly respects all indications of the specialist, *'cause when I go to the doctor, I ask when I should come next time. And he tells me when I need to come to be checked. And if the results are not good, then in 10 days I need to go to him and he gets it regulated…even 2-3 times per month.* **SI.2-i43pm2-cj**

Another chronic ill person, a 59-year-old woman tells us that she benefits frequently from the medical assistance, *Once every 3 months…Next month I'm supposed to go to get checked for my diabetes, now, on the 20th I have to go to get my heart checked…I haven't been to the hospital in a long time…And I'm suffering a lot…***SI.2-i23pf2-cj**

Some patients tell us that they have become more conscious of their health when they met ill people who had symptoms they would recognize in themselves.

*I had a sister-in-law who at the age of 63, which is close to mine, only after 2 years she told her daughter about her hemorrhage and she told me about this too…I told her it wasn't normally, that after menopause it's not right to bleed…She hasn't done anything about that for 2 years and then, of course it was too late. When I started bleeding, I told myself it wasn't right! And I went to the doctor…***SI.3-11f2is**

By analogy, patients understood that it could have been something serious, a fact that made them more responsible for their own health.

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

A 61-year-old man, with leukemia, also tells us that he understood the seriousness of his own illness through his brother's example. The man is convinced that the main culprits in the delayed addressing for medical assistance are patients:

> *It is very dangerous! My brother died because of it. He didn't ask for help in time…My brother…went to the doctor only 3 weeks before his death!* **SI.3-9m2cj**

We observe that patients are aware of the disease only when they perceive it visually, when they face with the experience of other people, with the seriousness and suffering caused by it in the material reality. It is an important moment, mentioned in the World Health Organization manual for health education (WHO, 1988, p.9) to consider in the implementation of measures for population education, when the example of a sick person is used to make healthy people to understand the seriousness of possible diseases and their prevention.

A particular aspect noticed in Rroma communities, different from the results collected from the general population, is that the disease is perceived as a shame, with an impact on human dignity. Grigore (2001) describes that in Rroma culture the disease is interpreted mystically, as a punishment or curse, often associating it with a sense of shame and, consequently with isolation from the community because, indirectly and unconsciously, it is a representation of spiritual and moral impurity For this reason, as some Rroma told us, they avoided medical advice or compliance with medical prescriptions, wanting to hide from the community that they are sick.

A 67-year-old Rroma man who worked all his life in marketing, apparently understands the seriousness of the diseases that he has, yet refused any treatment (medical or surgical) and intentionally does not follow medical prescriptions. It can be noted again, that the denial of poor health state is due to the patient desire to not decay in the eyes of his community by being sick, which would be a shame for him. The man says:

> *I daily drink 1-2 glass of vodka! I also drink a beer in the evening. I feel so good! I just think, that with 22 pills per day, I am not going to resist! That's why I gave up on medicines! I didn't talk to the doctor ... because I did not see him. I have not been to the hospital for whole year. But I do have diabetes.*

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

And my left foot hurts a lot. I have a hernia. I need to have a surgery but I'm afraid of it! **SI.2-i41pm2-cj**.

A hidden reason for this behavior can be observed, that is the fear of medical interventions, which probably is caused by the lack of basic knowledge about health and disease. The man cannot explain why he is so sick, telling shortly: *Well that ... only God knows ...* **SI.2-i41pm2-cj**. It is also a way to escape from his own responsibility for his illness, which finally is the result of his own behavior with a high risk for getting ill.

On the contrary, in the group of patients from general population, the illness is often interpreted as a frequently met state and ordinary to people. In the discussion with a 72-year-old cancer patient she tells us about her believe: *Any man can get sick! No matter who is he!* **SI.3-7f3cj**. A 53-year-old woman with lung cancer considers that disease is not a shame but that the disease can be seen as a divine trial to test the strength and faith:

Why to be ashamed!? Religiously talking maybe God wants to test my strength of bearing it, is a trial! But I have to fight and I'm the one who decide! **SI.3-1f2is**

Many patients consider that it is not a shame to be ill, and that the disease is not a situation that should be hidden from the community. From an interview with a 48-year-old man we understand that for him is not a problem to disclose his diagnosis:

... An oncologic problem is something human, is not from other universe! So ... it can strike anyone at any time because it is a disease. **SI.3-11m2cj**

It is an important difference to note especially for a differentiated approach to Rroma patient and to one from general population, based on the cultural peculiarities and traditions respected by them. Hiding the disease by Rroma patient because he perceives it as a shame in his community is an additional factor that motivates delayed addressing to the doctor.

Socio-economic context

Poverty was mentioned in both study groups as a frequent cause of getting ill. Obviously, the poor economic situation that our country was in the last 20 years has had an impact also on the behavior of the

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

population and we observe that the life quality standards have fallen essentially, especially of those from the rural areas. Passing through a long period of economic crisis (the communism), with severe deficit of food, with acute deficit of medicines and a permanent lack of money, a most part of the population got to settle with a minimum which guarantee survival, changing attitude towards their own well-being and health.

Many interviews indicated that the attitude towards disease and its treatment is significantly influenced by material wellbeing of each family. A 53-year-old woman with primary education tells us:

> *The lady asked me: do you have 8 millions for the surgery? If you have, you can come anytime and get the surgery! But from where I get 8 millions? ... Only once I went to the doctor ... is better to take a tablet or two and it calms me* ... **SI.2-i28af2-cj**.

The woman tells us that she reached the advanced stage of the disease and she cannot afford the surgical treatment. Also she tells us about her son, to whom she cannot afford the treatment of his sick foot:

> *Where can I go with him without money? I don't have ... If today he gives me 100.000, I still cannot manage because tomorrow I have to buy bread for children ... I cannot handle any more ... with so little pension that he has ... I cannot afford ... and I'm sorry for my child ... it hurts him, I go down to the pharmacy and buy some tablets for pain relief* ... **SI.2-i28af2-cj**.

A man who takes care of his sick mother and family with 2 minors children says he cannot afford medical consultation due to poor financial conditions. He explains how he manages to cope alone without medical assistance:

> *It happens that if I pick something ... I'm stuck ... I cannot move ... but until I get home ... I am recovering in 2-3 days ... so already I'm used to that pain* ... **SI.2-i40am1-cj**.

The requirements for own live quality are significantly reduced by their living conditions, so patients are pleased with the short-term improvements that occur periodically.

One 51-year-old woman from general population, who has cancer, recognizes that being motivated by material values she ignored the symptoms of the disease, choosing other priorities than her own health.

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

*Because I wanted to make a lot of money ... I think the biggest enemy in cancer is the stress, nothing else. ... I didn't know to say „enough" until I started to lose weight and I started to go to bed tired and to wake up more tired. What eyes I had! My face was telling to me: „You don't look fine!" It was true but I went forward. The work, work, work...***SI.3-9f2is**.

The population priorities are very strong influenced by the poverty. Due to the cult ingrained throughout the years, many people want "to be in the crowd" that often lead to excessive and unnecessary expenses, even with some obvious financial restrictions. The visit to the doctor means to invest time and money in something without immediate results and in the local cultural context it seems worthy only when there is really serious health problem, without being used to have a prophylactic control on own initiative.

Accessibility to health services

Assuming that society is partly responsible for the health of its members, however, does not settle the question of how it should fulfill this responsibility. Most of the discussions in public health ethics and health policies are focused on society's obligation to provide access to healthcare [9].

Daniels (2001) demonstrates the importance of equitable distribution of society funds and the principle of justice in society health maintaining, where social inequalities produce inequalities in access to health services with direct impact on population health.

When both groups were asked with what thoughts do they associate the concept of health system, often they mentioned difficulties to access the services. In this context, the son of a chronic patient expressed his regret about the health care reform, which reduced patient accessibility to specialized services. A Rroma man, who is fully integrated into the culture of the general population, is talking about the local family doctor who is not provided with medicines and can only refer patients to other doctors:

Well ... what I can say about this doctor ... poor of him, he doesn't have not even necessary things here ... he only has to refer! ... he can't do anything... but before all the necessary things were here ... **SI.2-i40am1-cj**.

In the conversation with a 61-year-old patient from the general population, he tells about the reduced and difficult access to specialized services. The patient had to travel 300 km in order to get to his doctor:

> *If I hit the road on the morning I am not sure if I can arrive there by evening. It's a very, very bad system. It's very difficult to go!* **SI.3-9m2cj**.

The man also accuses the doctors from the small cities who, in his opinion, deliberately complicate things:

> *They postpone you, refer you to others! They have private offices forcing you to go there, there are some things, I do understand this thing... Is not a problem for me to go there because I have what I have, but there are poor people... they cannot pay!* **SI.3-9m2cj**

The patient is telling us that he was satisfied receiving a better quality healthcare in larger cities. A major difference in the attitude of the doctors from public and private sector can be noticed. The man tells us his assumption that the doctors are intentionally providing poor quality services in the public sector to make patients turn to private clinics:

> *If you want to go to the hospital, is a problem to arrive there! So if the cardiologist starts his program at 10 am, even by 12 or 1 pm he may not come ... And there is a craziness, and there is a difficulty to receive tickets of access to the medical services, that not everybody can receive! And I had to go to the private sector. And in private sector if I was appointed at 6 pm, at exactly 6 o'clock I was entering! At quarter past six I was already going home! "* (SI.3-9m2cj). The patient is satisfied and feels respected when his time of appointment is respected.

The limited access to healthcare is also noticed in the discussion with a woman of 40, suffering from cervical cancer who has detected the tumor herself.

> *I was washing as always and encountered a bulge on the cervix with my finger. I told to my mother ... I did not have money to go to the doctor and I did not have even a family doctor. I told to my mother and father and I took money and went to consult a doctor....* **SI.3-10f1is**.

Facing certain financial difficulties and in the conditions of low access to healthcare, for a patient in rural region, it is difficult to go and consult a doctor for prophylaxis and screening purpose. This is a priority fact for the high rate of cancer detection in advanced stages, when the chances for cure are significantly reduced.

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

Full delegation of responsibility for health to the healthcare system

Most part of the population waits, in a passive way, for the healthcare system to assume full responsibility for the health of people, without involving themselves in prevention measures, activities in which the actors of the whole society should be actively involved.

We have encountered cases when the patient could not explain the disease he was suffering from due to, on the one hand, low capacities to understand complicated things and, on the other, the indifferent attitude towards the disease's severity. The things are left in the "God's will" this being, in a way, a refuge from the responsibility of decisions and actions which are imposed by the new state of illness. For instance, a 55-years-old Rroma man, chronically ill, who finished professional school, told us that he has very few knowledge about his disease. The only thing he knows about his illness is that he has to follow the doctor's prescriptions – the diet and medications (SI.2-i39pm2-cj). It is relevant the fact that this patient does not show any interest in finding out more about what has happened or happens to him in the present, leaving all choices to be made based on doctor's competence and decisions.

What would be the roots of such passive attitude of the patients? Why the population expects major actions from the healthcare system, without showing interest and participation, even when this concerns, directly, his health? We consider that one of the reasons of this specific attitude of the population in relation with the healthcare system is the paternalistic attitude promoted in the healthcare system during many years by a totalitarian regime, the values and ideology of which has left a significant effect on the East-European culture.

Over more than half a century the principles of socialist or "collectivist" ethics with a strong paternalistic character were promoted in the society. The collective assumes full responsibility of decisions for the determination of the individual benefit. In this type of relationship the individualized "Ego" is refused to determine its fate and to be responsible for it. The healthcare expenses were fully covered by the state and only the state could assume the right to decide what range of services is necessary for the population, when and how should they be

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

provided. In a way, the decision for the population goodness was entirely a community priority.

The fact that healthcare services must be paid for provokes dissatisfaction among some interviewees. A 71-year-old Rroma man tells us indignantly: *Simply – money is necessary! Everywhere, anywhere you go!* **SI.2-i24am3-ur**. The old man speaks with regret about the communist regime, when the healthcare was fully insured by the state. The same regret can be noticed in the discussion with an ill man of 63: „*In our days, if you do not give money, you are not offered consultation*" (SI.2-i12pm2-lg). The patients are outraged by the new system of services provision, which places the patient in the role of client and would prefer to have all conditions insured in a centralized way by the state.

The paternalistic attitude of the state and of the system during the communist regime has radically changed the perception of own individuality of the patient from this space. The effect of this approach can also be found strongly impregnated in the doctor-patient relationship system. The problem of patient information was considered rather of a technical order than an ethical one. In cases when the consent was necessary from the patient or his relatives the concept of „sacred lie" was preferred, which, till 90s, was even propagated in the medical deontology. Furthermore, the curriculum for undergraduate medical education, until recently, did not contain programs for training the future doctors in bioethics and fundamental principles of Human Rights, and such basic definitions like *informed consent, patient information, confidentiality, the right to choose, the right to information*, etc., were interpreted from the perspective of community interests and the benefit of public health, fact that, today, generates more and more conflicts. Morar (2007) describes the impact of excessive protective attitude of society to its citizens, as a result of which actual doctors are placed in conflict and double loyalty situations.

However, switching from a public health centralized system „Semashko" type to a health insurance system, it was expected an increasing individual responsibility for one's own health. Nevertheless, as it is concluded in the Report of the General Assembly of the College of Physicians of Romania (Astărăstoae, Oprea, Vicol, 2010), so far an assessment of the implemented reforms in this aspect has not been

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

realized. Moreover, as a result of the implemented changes a severe imbalance of the ratio between the **social responsibility for health** (the social duty to promote a collective effort focused on improving the health of population measured by the decrease of morbidity and mortality in the society) and the **individual responsibility** (the duty and individual capacity to take care of one's own health) was established, the state abdicating from its role as guarantor of the right to health.

A low patient responsibility for their own health we have noted in many cases in our study. Patients become consumers of health services, to the extent of system`s offer and personal needs for the moment without assuming the decisions through caring out some preventive actions. A 68-year-old man, who takes care of his seriously ill wife, though he regularly goes to the doctor instead of his wife, does not do the same for himself for preventive purpose:

> *This year I have not been... I have not been for about 5 years ... I go twice a month for my wife* ...**SI.2-i30am2-cj**.

Even in the situation when he directly faces the reality of a severe disease, the illness, for this man, anyway is accepted only when it is manifested symptomatically without taking any measures of early detection.

Many of the interviewed persons assume the responsibility for their health only when the disease is fully manifested. A man of 59, suffering from lung cancer recognized his unhealthy behaviors and ignored advises concerning the protection of his own health. Being a heavy smoker, he found the strength to abandon vices on which he depended but it was too late to recover:

> *And when I have to get up next day in the morning, I say to myself, „get up if you can! ... I stayed in hospital ... After that they found that I had a heart disease... I have not drunk since then, I have not smoked since then... 40 years I used to smoke!* **SI.3-14m2is**.

It is very suggestive the message expressed by some of the surveyed both chronically ill persons with severe diseases, as well as their caregivers who see the sufferings of the beloved ones. When asked what they would like to say to others they recommended to regularly consulting the doctor. „*Go to the doctor, so that nothing bad happens to you or*

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

you do not get sick" – says a woman of 54 who takes care of her husband and her mother suffering from cancer (SI.2-i38af2-cj).

In the same context, a 42-year-old man, suffering from rhino-pharynx cancer says:

> *Any person, who has a little, little, little pain, in his head, in his legs, in his nose should go in any case to consult a doctor, to go to the doctor! ... I caught colds many times, I have not taken a pill, I have not taken anything, and now I regret somehow, because if I felt I have caught a cold I had to go to the doctor* ...**SI.2-i35pm1-cj**.

The same message is expressed by a man of 46 from the general population, diagnosed with lymphoblastic lymphoma and multiple metastases, who would like to tell everybody what he learned from his own ignorance towards his health:

> *Each person should go to the doctor as soon as possible! So if one sees only a pea on his body, immediately to go and make the biopsy, and not to do like me, because I stayed one year and four months with this on the elbow* **SI.3-11m2cj**.

Direct confrontation with the state of illness makes people understand the importance of individual responsibility that must be assumed by each person to prevent illness. Messages sent by the sick are relevant but they do not have the power of persuasion to change a society`s attitude and mentality.

In this context, an ethical conflict is obvious when holding individuals entirely responsible for their own health the adequate conditions are not offered by the health system for physical persons to undertake health relevant actions and choices. More of that, as Wikler (2002) says, it is unfair to hold individuals responsible for their own health if they cannot make sound health-related choices because incompetence to understand the problem, addictive behaviors or cultural peculiarities (customs mandatory to respect).

Although individuals should play an important role in maintaining their own health, they should not be held entirely responsible for it. Thus, the responsibility for health, as Cappelen and Norheim (2005) confirm, reffers to both individuals and society, and it follows that society should also be involved in promoting health and disease prevention.

GRAMMA, R. PÂRVU, A. ENACHE, A. ROMAN,G. DUMITRAS, S. IOAN, B. Factors with an Impact on the Perception of the Value of Health and Disease in the Romanian Cultural and Socioeconomic Context,
Postmodern Openings, Volume 4, Isuue 1, March 2013, pp: 117-139

At the same time, we come to the conclusion that the current priorities of healthcare system are focused mainly on the control of medical costs as a key element to improve the quality of healthcare and, in the conditions of insufficient funds, the activities of prevention, health promotion and education are left on the waiting list.

Conclusions

The results of the study show that there are two problems that worsen each other: low individual responsibility, due to a lack of health education, specific cultural values and traditions and gaps in development of health system policies and strategies, motivated by a lack of finance and a unilateral approach to the problems.

It is difficult to prioritize these two aspects. Which one is more important to be solved to improve public health outcomes? As Wikler (2002) and Resnik (2007) affirm, the social responsibility arises from the individual responsibility and vice versa, one cannot take chance of success without the other.

Parsons (1975) in an attempt to argue strategies to strengthen public health show that when social responsibility for the individuals` health is emphasized too much, there is a decrease in individual responsibility of the members of society. Making society fully responsible for the health of its citizens, as a result we get passive reactivity and total dependence on the health system of persons when they get sick.

Many authors confirms, Callahan, Koenig & Minkler (2000) and Beach, Meredith, Halpern, et al. (2005), that responsibility for health should be a collaborative effort among individuals and the societies in which they live. Individuals should care for their own health and help to pay for their own healthcare, and societies should promote health and help to finance the costs of healthcare.

Though access to care tends to dominate discussions of social responsibility for health and often receives the largest portion of society's resources, the importance of other component of public health as health promotion and education should not be ignored. The impact of social

inqualities on acces to these servicies, in accordance with Dahlgren&Whitehead (2006), must be considered always.

Thus, besides improving policy measures taken at the health system level, the influence on the population level, responsible for its decisions and consequences on the health, is very important. People should be educated and empowered to monitor their own health.

However, there is a need for developing coherent programs adapted to cultural particularities of the population to acquire health behavior skills. Educating a rational use of health services should be the main tool to change the population 'vision on health and disease

Acknowledgement

This research was developed within the project „Postdoctoral studies in the field of health policies ethics" (POSDRU/89/1.5/S/61879) co-founded by the Social European Found through the Operational Program for Human Resources Developing 2007 – 2013. Priority axe „Education and professional training supporting economic growth and society development based on knowledge". Major field of intervention 1.5 „Doctoral and postdoctoral programs in supporting research".

Bibliography:

Astărăstoae, V., Oprea, L., Vicol, M. (2010). Responsabilitatea socială şi individuală pentru sănătate în sistemul sanitar românesc. Raport la Adunarea Generală a Colegiului Medicilor din România, Bucureşti.

Beach, M.C, Meredith, L.S., Halpern, J et al. (2005). Physician conceptions of responsibility to individual patients and distributive justice in health care. Ann Fam Med; 3 (1), 53-59.

Callahan, D, Koenig B, Minkler, M. (2000). Promoting health and preventing disease: ethical demands and social challenges. In: Callahan D, ed. Promoting healthy behavior. Washington, DC: Georgetown University Press, 153–170.

Cappelen, A., Norheim, O. (2005). Responsibility in health care: a liberal egalitarian approach. J Med Ethics. 31 476–480.

Dahlgren, G., Whitehead, M. (2006). European strategies for tackling social inequities in health: Levelling up Part 2. WHO Collaborating

Centre for Policy Research on Social Determinants of Health, University of Liverpool. WHO Regional Office for Europe, Copenhagen.

Daniels, N. (2001). Justice, health, and healthcare. Am J Bioeth 12–16.

Eckersley, R.M. (2007). Culture, spirituality, religion and health: looking at the big picture. Med J Aust; 186 (10): 54.

Education for health. A manual on health education in primary health care (1988). Geneva, World Health Organization. Retrived from http://whqlibdoc.who.int/publications/1988/924154225X_eng.pdf

Georgiu, G. (2001) Filosofia Culturii. Bucureşti: Comunicare.ro.

Grigore, D. (2001). Curs de antropologie şi folclor rrom. Introducere în studiul elementelor de cultură tradiţională ale identităţii rrome contemporane. Bucuresti: Credis,.

Mc Laughlin, L., & Braun, K. (1998). Asian and Pacific Islander cultural values: Considerations for health care

decision-making. Health and Social Work, 23 (2), 116-126.

Morar S. (2007). Aspecte etice ale relației medic-societate. Revista Română de Bioetică, 5 (2), 37-41.

Parsons, T. (1975). The sick role and the role of the physician reconsidered. Milbank Mem Fund Q Health Soc. 53, 257–278.

Resnik D.B. (2007). Responsibility for health: personal, social, and environmental. Med Ethics, 33(8): 444–445.

Wikler D. (2002) Personal and social responsibility for health. Ethics Int Aff. 16 47–55.

World Health Organization Report: Reducing risks, promoting healthy life. (2002). Geneva: WHO. Retrived from http://www.who.int/whr/2002/en