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HEALTH POLICIES AND THE ROMANIAN GYPSY COMMUNITY

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ABSTRACT

This research aims at evaluating how health care policies affect the life of the Roma minority in Romania. The Roma or ‘gypsies’ are the second largest minority in Romania and the one most discriminated against. Living in sheer poverty, the life expectancy of the Roma is 10-15 years shorter than that of other citizens of Romania, revolving around 50-55 years. The Roma suffer—most commonly—from cardiovascular, digestive, and lung diseases. Besides health problems, the Roma community has to face illiteracy and a high rate of unemployment as well.

In the present research the impact of specific internationally financed Romanian health programs and policies towards gypsies will be evaluated. Both quantitative (surveys) and qualitative (interviews) methods will be used to give a clear view on the impact of health policies.

The initial presumption is that these programs and policies do not truly reach out to the Roma community and that they do not have the expected impact. The results will be correlated with Norman Daniels’ just health care theory and the research will then analyze the connection between healthcare and life opportunities of this community.

INTRODUCTION

Romania has an upper middle economy according to the World Bank’s 2008 country classification, with a GNI per capita of 6150 US dollars in 2007 (World Bank, 2007).

Since the fall of communism in 1989, the country has experienced a period of harsh transition which led eventually to the accession to the European Union in 2007. The end of communism brought not only democracy and a market economy,

¹ Romani greeting; meaning: Be healthy, Be lucky!

but significant disparities in living conditions and poverty for some groups. And one such vulnerable group is the Roma minority.

Romania has the largest population of Gypsies in Central and Eastern Europe. According to the last census, in 2002, their number officially is around half a million (2.5% of the population), but the unofficial estimates are much higher, around 1.5–2 million people (Bárány, 2002).

The history of the Romanian Gypsy community

The history of gypsies in Romania is one clouded by slavery, darkness and poverty. The first written accounts of this community were created in around the eleventh century (Crowe, 1991), when the Roma arrived in the regions of Wallachia and Moldavia. Gypsies were enslaved from the fifteenth century onwards until the middle of the nineteenth century. In this period they were heavily exploited, since they were known to be good craftsmen and also musicians. This exploitation in many cases was followed by torture and bad treatment. (The World Bank, 2005: 90)

During the eighteenth century in Transylvania (then part of the Austro-Hungarian Empire), gypsies were forced to speak the language of the majority and the landowner had to offer them small lands in order to oblige them to work in agriculture. These rules were implemented as a means of transforming the Roma's nomadic way of living.

Then, in the nineteenth century, slavery was abolished, but many Gypsies had to face poverty again. Some of them moved to the outskirts of cities and villages and some returned to the traditional nomadic lifestyle.

During the Second World War the Holocaust reached the Roma community too, yet for a long time nobody addressed this issue. It is difficult to know how many Roma were killed, but the numbers revolve around 300,000-500,000. In Romania alone an estimated 25,000-36,000 Gypsies were transported to camps in Transdneister (now part of Ukraine) where they died of cold, hunger and improper living conditions (Crowe, 1991).

In the communist period, according to the Party line, everybody enjoyed equality. But this equality meant assimilation of minorities, and as a consequence Gypsies were not allowed to study in their native language or to preserve their culture. Yet, on the bright side, the majority of the Roma had a job (as unskilled workers in factories) and shelter, which meant a rise in living standards.

But then with the fall of the dictatorial regime an even larger discrepancy came to the surface between the majority of the population and the Roma. With the introduction of the capitalist economy, the Roma lost their jobs and their small, but secure income. Adding to this—during the transition period—they had to face a rise in nationalism and discrimination.

Since the middle of the 90s international organizations have started off programs intended to improve the conditions of the Roma in education, health, employment and housing. There is still a lot of work to do.

HEALTHCARE POLICIES IN ROMANIA

The drift from communism to democracy brought a great impact on the health system of Romania. When under communism, access to health care was in general universal and free; the step to a market economy meant crisis, new policies and chaos.

In 2000 a new health insurance system was implemented in Romania. Under this system all the citizens of the country had to be registered with a family physician to be eligible for health care. The insurance works by payroll tax deductions for those who work in the formal sector, while those who are self-employed have to make contributions on their own. Beside these taxes, citizens have to pay for some drugs, transportation to health care facilities, and official and unofficial out-of-pocket payments (bribes) to doctors and nurses.

Since many of the Roma community do not have formal working places, they do not pay taxes or contributions for health insurance. Thus they do not figure in any register so when in need of health care they must pay. Since many Roma cannot afford this, they have to struggle with poor health conditions. It is a vicious circle which has proven increasingly hard to break:

Poor living conditions, such as overcrowding and lack of adequate sanitation facilities, make Roma communities more susceptible to infectious diseases than other groups. Reports of epidemics of hepatitis, tuberculosis, and parasitic diseases were common during and after the socialist period. Skin diseases, such as eczema, are also common. The last reported cases of poliomyelitis in Bulgaria, FYR Macedonia, and Romania were all in Roma communities (OSCE 2000).

Adding to this there is a heavy discrimination and a negative attitude towards this minority practiced by the health providers: “While there are positive examples, this relationship is more often characterized by miscommunication, distrust and, in some

cases, discrimination [...] The attitudes and perceptions of both patients and medical staff can have a significant impact on how health needs are conceptualized and the quality of service delivery.” (The World Bank, 2005: 108)

Yet the Romanian government has made important steps in trying to assess the healthcare of the Roma community. Although this is not the only reason, some of these measures have been taken up since Romania is participating in the so-called *Decade of Roma Inclusion 2005-2015*: “The Decade focuses on the priority areas of education, employment, health, and housing, and commits governments to take into account the other core issues of poverty, discrimination, and gender mainstreaming.” (www.romadecade.org)

Through this program, so far two reports have been published on the health status of the Roma minority in Romania. The one published in 2005 deals with the Roma Health Mediator Program, and the other one is an assessment of HIV and TB programs. Both of the reports agree that “unhealthy living conditions are one of the major causes of poorer health among Romani populations, particularly in the many ghettoized settlements. These conditions include sub-standard and crowded housing; little or no access to clean water, garbage collection, and roads; and geographic isolation. Other social issues, such as poverty, discrimination, and low position in the social hierarchy play an equally important role in shaping Romani health.” (Mediating Romani Health, 2005: 10)

This means that in addressing Roma health issues, governments have to deal with an interconnected, complex issue of unemployment, housing, education and health problems.

One of the most important health policies has been the introduction of the so-called mediators in the public health system. “Members of the Romani community themselves, RHMs [Romani Health Mediators] aim to improve community health through (1) mediating between Romani patients and physicians during medical consultations, (2) communicating with Romani communities on behalf of the public health system, (3) providing basic health education, and, (4) assisting Roma in obtaining the health insurance or identity documents necessary to visit the doctor.” (Mediating Romani Health, 2005: 10)

Some programs try to deal with the high incidence of tuberculosis and HIV (Roma Decade National Action Plan on Health), but the 2001 Strategy of the Government of Romania for the Improvement of the Roma Situation does not mention TB or HIV/

AIDS. Yet we have to acknowledge that the mere attempt to develop a governmental strategy proves that the state is interested in solving these problems.

It is still a question to what extent these programs and policies confront the conditions that cause health problems among Roma. According to one report on the mediator program: “results have not been effectively leveraged to bring about systemic change, and program activities are not sufficiently oriented toward remedying the structural inequities that shape Romani health in the first place. Integrate Romani health needs into overall health and social services reform.” (Mediating Romani Health, 2005: 11)

THEORETICAL FRAMEWORK

Bill Jordan (2006) sees the importance of social policies in their strength of supplying a certain degree of security and protection. People need proper health care to function well. Although the Washington Consensus model was meant to “discourage governments from trying to adopt redistributive policies or seeking to give their citizens economic security” (Jordan, 2006: 30), Samuel Bowles argues that “[...] government provision of both health and education services and unemployment benefit can increase productivity, employment and wages by more than the cost of supplying these services. These institutions are all complementary; workers consider it worth going to school and looking after their health if employment is relatively secure and a subsistence income is guaranteed during spells of unemployment.” (Cited in Jordan, 2006: 35)

Research on the impact of health policies for the Roma minority might start with the question of whether access to health care is a “requirement of social justice, or is it simply a matter of social policy that some countries adopt and others do not” (Daniels, 2008). If we choose the social justice path, then we have to consider the need for positive discrimination for the most vulnerable, in this case, the Roma minority. According to the Webster’s Online Dictionary, positive discrimination can be defined as those measures that are targeted at a particular group and are intended to eliminate and prevent discrimination or to balance disadvantages arising from existing attitudes and behaviors,.

To provide an answer, it might be useful to deal with the egalitarian theories which try to express the idea that all humans are equal in fundamental worth and moral status (Arneson, 2008). One of the highlights of egalitarian doctrines is the

equality of opportunity ideal. In connection with this, John Rawls has formulated a famous and debated theory, and that is the principle of equality of fair opportunity (EFO).

In his theory, Rawls presents a society in which only native talent and ambition can make a difference in one's chances to succeed in life. In a way, he speaks about a sort of classless society. John Rawls' theory is appealing because "EFO also opposes racial and sexual and similar prejudices that work to deprive disfavored individuals from enjoying opportunities to become qualified so that they would benefit from formal equality of opportunity." (Arneson, 2008)

Yet this theory cannot fully serve the purpose of the present research since we have to connect the ideal of equality of opportunity with that of health care for all. And Norman Daniels makes this connection in his book, *Just Health Care* (1985).

He advances a theory of justice in the distribution of health care. Daniels extends Rawls's appeal to a principle assuring fair equality of opportunity. One of his main arguments in favor of "universal access to some forms of health care builds on the contribution made by health—and derivately by health care—to the opportunities people can exercise." (Daniels, 2008) Since this theory builds on Rawls' justice as fairness claim, which states that we have the social obligation to protect the opportunity range of individuals, consequently it could posit that we have the obligation to promote and protect the normal function for all people. At the core of his theory we find what he calls species-typical normal functioning, which means that all human beings have certain needs -like food, housing, health care- irrespective of preferences about their ways of life. And he links species-typical normal functioning to opportunity. "Species-typical normal functioning is morally significant because it influences the size of an individual's share of the normal range of opportunities in a society." (Jacobs, 1996: 321)

Therefore in his theory the goal of health policy is that all people have to function in a normal way. As a consequence this goal is both egalitarian and maximizing.

When choosing a path for research we have to deal with this path's (theory's) essential strengths and weaknesses. One of such weaknesses of the just health care theory is that it is too broad. Daniels acknowledges this problem: "we lack prior agreement on more fine-grained principles that tell us how best to protect opportunity in this context. Because we lack a consensus on such principles, we should engage a form of procedural justice or fair process to yield fair outcomes." (Daniels, 2008)

Another defect might be the one denoted by Lesley Jacobs (1996). This weakness concerns the fact that Norman Daniels deals only with ill health in his discussion about fair opportunity in life and forgets about another natural disadvantage: the lack of certain talents or skills. The author argues that both ill health and natural talents have to be linked to fair opportunity. Although Jacobs' observation is pertinent, in the present proposal we are interested in the strict problem of access to healthcare and how this influences people's life, thus we will not deal with the question of natural talents or skills.

All these shortcomings are acknowledged and the consequences will be dealt with in the research report.

To conclude, Norman Daniels' work is considered to be the most suitable for this topic and his main argument- that health has a major role in one's opportunities in life, thus there should be an equal distribution of health care services- a starting point in researching the impact of policies for Gypsies.

THE RESEARCH QUESTIONS

There are many scholarly discussions about justice and equality of opportunity. As stated above, Norman Daniels takes these discussions to the field of health care.

The research on the impact of health programs for gypsies can provide an empirical example for this discussion. Daniels' conclusion might be considered a milestone: "[...] a health care system should be designed to even out differences among individuals in terms of personal health in the same way that the education system should be designed to even out differences between similarly talented individuals from different socio-economic classes." (Jacobs, 1996: 330)

So we reckon that through equal and just health care Roma could have better opportunities in life. Consequently, if Roma could enjoy equal opportunities in healthcare they could have better chances to achieve so-called "species-typical normal functioning."

The Decade of Roma Inclusion 2005-2015 has precisely this goal for Roma to be able to enjoy the same opportunities as the majority of citizens in Central and Southeastern Europe. There remain a few years to see whether the Decade will be successful.

The questions therefore will be as follow: Did the specific health policies and programs have the expected impact for the Roma community? If so, is the

improvement in health condition a background condition for fair equality of opportunity for this community? But Daniels' theory could be checked even if the impact hasn't been the expected one since the next question would then be, Does this lack of equal opportunities in health care have a major role in their opportunities in life?

It is anticipated that that the answers of the research questions will provide comments on the larger question of justice and equal opportunity. It is also expected that these answers will support Daniels' theory but that they will also prove that—in the case of Roma—access to equal healthcare only will not guarantee better opportunities in life.

RESEARCH METHODS

For answering these questions several quantitative and qualitative methods will be used, among them surveys, content analysis and interviews. Since the purpose of this research proposal is to measure the impact of health programs and policies, surveys and interviews are regarded as the most useful procedures. These methods have been chosen because impact is not understood here purely as a measurable unit (surveys) but also as one that has a highly subjective value (interviews).

This combination of methods is to be pursued to obtain greater knowledge about the issue of the study, but it could be used to mutually validate the findings of these approaches. An additional option would be a literature study to comprehensively understand the problem through academic articles and reports.

Regarding this topic another author, István Pogány, in his study (2004) about the human rights of the Roma community used the interview as a method to bring his research closer to people: "This approach provides a contextual depth to the analysis and avoids the glib generalisations and disparaging stereotypes that can undermine such accounts." (Clements, 2005: 161)

In another study, which focused upon rural women seeking for health information in remote areas, the researchers used semi-structured interviews to discuss the then mismatch between these women's lives and the Canadian policy assumptions supporting the development of electronic health strategies. (Harris, Wathen, 2007) This last research is particularly interesting because it demonstrates that often there is a discrepancy between the aim of the policies and the actual lives of the people in question.

In a qualitative study of Roma communities in Romania researchers used similar techniques to portray the actual living conditions of Gypsies (The World Bank, 1999). In this research they were interested in drawing a picture of Roma life and their access to social services. The researchers worked with interviews, site visits and additional primary and secondary materials which were afterwards analyzed.

For identifying such and similar problems, in the course of the fieldwork, interviews will have to be conducted with members of the Roma minority, people taking part in the health mentor programs and health practitioners. It would be advantageous to interview a large number of Roma (from different parts of the country, coming from different groups of Roma). By interviewing people of Roma minority, it is more likely to discover the personal viewpoints on the topic of health and opportunities. Thus open-ended interviews will be used which are closer to everyday interaction and might give a better insight to how these people think and feel about healthcare. Although the researcher has to work with a large degree of subjectivity, these open-ended questions can provide a complex view on the impact of policies people really experience.

During fieldwork focus groups are also to be considered since they are particularly useful when discussing taboo subjects, and Roma health care is in many cases this type of subject. Adding to these focus groups could be used for discovering common processes of problem solving in this minority (Flick, 2006).

In the World Bank research mentioned earlier there were made 65 in-depth interviews with key-informants and more than 165 with Romani people individually and in groups. The large number of interviews was needed to discover the general access of Gypsies to social services.

Since this study has a precise target (health care) and the time and fund limit is shorter, it is assumed that around 40-50 interviews will be carried out in total. Still, this number of interviews is considered to be enough for the purpose to be accomplished.

Another chosen method is the survey. Although not always accurate when dealing with this community, surveys could help in understanding how successful the different programs and policies were in preventing or curing illnesses. Sometimes it is helpful to use national level data to provide a context to qualitative research. Adding to this, surveys might back up the findings of the interviews or they might contradict

those. Either way these findings together with the correspondence/ contradiction will be analyzed in the report of the research.

The combination of these two methods is considered useful to show the impact of the health policies and how this impact influenced or not the fair opportunities of Gypsies.

Research plan

Time-frame: the fieldwork could be estimated to be completed in about three-four months, during which interviews will be done in several rural and urban areas in Romania. After completing the fieldwork, another three months will be needed for the completion of the whole project (data analysis, conclusions)

DIFFICULTIES AND SOLUTIONS

One of the difficulties in this research is that the Roma groups are somewhat closed communities. Another problem might be linked with certain taboo topics in healthcare such as vaccination or women's health issues. These matters apparently are not discussed openly and there is a sense of shame when they are taken up (Council of Europe & European Monitoring Center on Racism and Xenophobia, 2003).

For handling the first problem: the researcher has to be accepted by the community in order to get factual answers to these difficult questions. For solving the issue it might be useful to get into contact first with the representatives of some Romani NGOs who could help to make the way to the community smoother. By using "contact persons" it could be easier to get closer to the group. Another option would be to collaborate with a Roma researcher or research assistant. It would probably give a better insight since people will be more open to someone from their own community.

With regard to the taboo topics: although focus groups should be heterogeneous, it could be more opportune if there were only single-sex groups. Thus sensitive topics (women's health, for example) could be easier discussed without the restraints of gender-roles so powerful in the Roma culture.

Lastly, one of the biggest issues is the victimization of this community. Usually Gypsies themselves (but others as well) tend to be highly biased when talking about discrimination and their problems. Although this is normal to some extent, the researcher has to deal with this problem in a neutral way. In solving the issue, focus groups with health practitioners- nurses, doctors- will be used. Thus, by, choosing to

consider the situation from the practitioners' point of view, the results and conclusions will be more accurate. This method could be much more effective since in the above-mentioned World Bank qualitative study (1999) researchers found that while the Roma blame the medical staff for discriminating against them, practitioners consider that communication with Gypsies is difficult and they distrust the Roma:

I do not register gypsies as a family physician. I do not accept gypsies. . . . They come here and ask for money, ask for medicines. . . . They have a lot of nerve. You have to keep an eye on them when they enter here. I do not think they are poorer than other people. They go to Hungary with business; they probably have more money than we have. They go by car to ask for social aid. (The World Bank, 1999: 108)

Ethical considerations

The study will be conducted in accordance with a pronounced ethical awareness. The rules and guidelines of the research follow the Swedish Research Council's recommendations.

Participants in this research will be previously informed about the background, the purpose and the voluntariness of this study. The information will be adapted to the participants' general circumstances, especially taking into consideration the high rate of illiteracy in this community. Adding to this we will consider and respect the cultural norms existing in the Roma minority. Facing the problem of illiteracy and cultural differences will be a step-by-step process, first talking to the leaders of the community or a specific NGO-leader to inform them about this research. Subsequently, similar discussions will be conducted with individual subjects.

Although it is important to apply the research ethics standards, we find it equally important to develop these standards so that they are relevant and sensitive to the specific context of the Roma community.

CONCLUSIONS

The aim of this research proposal is to shed light upon the experienced impact of health programs and policies targeted at Gypsies in Romania. By examining this impact, the next step will be to prove whether just health care and positive discrimination means in reality more opportunities for this minority.

The objective of all these policies is the inclusion of the Roma community in society, but the question is whether they are successful and if not how they can be changed in order to fulfill this ambition.

The World Bank gives some guidelines, but they seem easier in theory than in practice:

Policies should balance three related sets of objectives: first, increasing economic opportunities by expanding employment participation; second, building human capital through better education and health; and third, strengthening social capital and community development through increased Roma empowerment and participation. (The World Bank, 2005: 192)

The research will end with a discussion of the policy implications of the findings. It will show the positives and negatives of the programs and policies but mainly it will hopefully give an insight on how the people affected see these. And this insight could help policymakers in understanding and shaping the programs for the needs of the community. One of the biggest problems of policies for the Roma is that they usually neglect the cultural difference between the majority of citizens and the Roma. Through this research it is aimed that the administration in charge will better understand how Gypsies themselves feel about the importance and impact of such programs.

We believe that this research approach is feasible and that if everything runs as planned, it will be successful. The data collected through these methods will fill a gap of communication between policymakers and the Roma people. The proposed research will make an important contribution to existing, but limited knowledge. We believe that the success of this research will have a major potential in improving health care policies for the Roma community.

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