

Postmodern Openings

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

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

The Rroma Family in the Context of Terminal Illness

Ștefana Maria MOISĂ,
Mariana ENACHE,
Gabriel ROMAN,
Andrada PÂRVU,
Rodica GRAMMA

Postmodern Openings, 2013, Volume 4, Issue 1, March, pp: 73-86

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

The Roma Family in the Context of Terminal Illness

Ștefana Maria MOISĂ¹,
Mariana ENACHE²,
Gabriel ROMAN³,
Andrada PÂRVU⁴,
Rodica GRAMMA⁵,

Abstract

The whole existence of the rroma, regardless of the particularities of their lineage, is modulated by their ancestral culture, which implies respect for the family and the community. The rroma family is usually extended, offers support to its members in any situation and represents the basic unit of the society.

In this paper authors present the results of a qualitative study that aimed to describe the attitudes, behavior, opinions, beliefs, knowledge and values of rroma that face incurable diseases from two communities in two different counties of Romania, Iasi and Cluj. Study participants were severely chronically ill patients and their families and data were collected using individual interviews.

Data have shown a particular way of thinking of the people that were interviewed; they counted on family help in any situation and often on community help.

Keywords: *rroma; family; community; disease*

¹ Center of Ethics and Health Policies, Iasi, Romania; University of Medicine and Pharmacy „Gr. T.Popa”, Iasi, Romania

² Center of Ethics and Health Policies, Iasi, Romania

³ Center of Ethics and Health Policies, Iasi, Romania

⁴ Postdoctoral Researcher, Center for ethics and Health Policies, UMF "Gr. T Popa" Iasi Center of Ethics and Health Policies, Iasi, Romania; Assistant Professor, Hematology Department, "Iuliu Hatieganu" University of Medicine and Pharmacy, Cluj-Napoca, Romania

⁵ Center of Ethics and Health Policies, Iasi, Romania

Postmodern Openings

Introduction

In the Rroma traditional culture, everything gravitates around the family, the basic unit of social organization, a system of familial groups, an economic unit where solidarity flourishes, an educational structure. (Nistor D.M, 2011) The lay religion of the rroma is Romanipen, the rromani law, a system of community rules and concepts that gravitates around the identity model of the traditional culture: *the family*. The community itself is an extended family, based on three kinds of kinship: by blood, by alliance and by affinity.

The family is a system of interacting personalities that discloses interacting relationships between the attitudes and behaviors of family members. Any divagation from community norms unavoidably leads to internal, familial sanction and more importantly, to community sanction, the stability and identity of which ultimately depend on family structure. Community action over the family is more powerful if boundaries between the family and the community are more flexible, like in extended families that have the characteristics of a community itself, where groups of descendants owe loyalty to each other because of the bilateral relationships of complementary and alliance kinship. (Grigore D, 2010)

Material and method

We have performed a qualitative study using as an investigation technique the individual semi structured interview with severely chronically ill rroma patients and their families, in order to understand the attitudes, behaviors, opinions, beliefs, knowledge and values of rroma with untreatable diseases.

The study was performed in rroma communities in two Romanian counties, Cluj (communities in Cluj Napoca, Mera, Bontida) and Iasi (communities in Morilor, Vantu, Dancu, Pietris-Dolhinesti, Zanea-Ciurea, Zmeu-Lungani). 48 interviews were performed, out of which 25 in Cluj county and 23 in Iasi counties, with equal proportions of patients and family members.

Interviews were performed inside communities, at participant's homes. Researchers' access into communities was possible with the help of community leaders, medical associations, family doctors.

Study participants were selected from different chastes, according to regional characteristics. In Iasi, kalderash, spoon makers and brush makers were interviewed (closed communities), while in Cluj selected participants belonged to more open communities (Hungarian rroma or Romanian rroma) from Cluj-Napoca, Mera and Bontida.

Interviews were tape recorded and written down. Some interviews in Cluj were performed in Hungarian language and then translated into Romanian.

Interviews contained questions about previous illness experience (as a patient or family member), end of life practices, diagnose communication and decision making, coping strategies and attitudes towards terminal disease and death, illness perception by the family and community, family and social support offered to the ill.

Research methodology and interview guide structure was approved by the Research Ethics Committee of “Gr. T. Popa” University of Medicine and Pharmacy in Iasi.

Study participation was voluntary, no payment was offered. Participants signed the informed consent form before the interview. They were ensured of the right to withdraw from the study at any time or not to answer certain questions if they did not want to.

Data were subject to phenomenological and content analysis.

Results and discussions

The results of the study showed that the pattern of the investigated communities is to value the experience that comes with age, which is treated with respect and admiration that leads to special authority and privilege.

Inter and intra-community relationships

To be part of a family means to be protected, but also to be responsible. Elderly people and children were always special categories in the rromani culture. Respect for the old age is a basic principle of these people. Grandparents and parents occupy a position characterized by

Postmodern Openings

respect, admiration and privilege and represent group authority. A distinctive trait of the rromani behavior lies in the relationship between the young and the old, a relationship based on filial devotion:

If father said: get into that fountain, because it's good to be there! Then I would get in there! SI.2-i5af2-cl, or For her (mother) and father, I would give my life! SI.2-i9af1-cl

The extended family lives together, and most of the time, the whole neighborhood is inhabited by kin: rooms are added for newlyweds to the house of the groom's father or a new house is built in the yard of the parents. The principles of living together are *mutual help* and *collective responsibility*. A person only exists to the extent he/she is recognized by the community and a statute, rights and obligations are offered.

Most rroma do not identify with the general rroma population, but with their own lineage. The extended rromani family is a social organism, made of interdependent cells, where kinship relationship is fraternal, equal and characterized by cooperation. Inside the rroma family we can identify several specific traits, like: getting married to a person from the same lineage, specific birth, marriage and death rituals, behavior and relationship ways according to Rromanipen.

The whole rroma existence is influenced by their own traditions. They establish the roles within the family, the duties of each member, who has the authority and power to decide; how family members should dress according to their sex, age and civil status; personal and object hygiene indications; rules of acting in important moments of life, like birth (behaviors and attitudes accepted or forbidden during pregnancy and until the child is baptized, the impure state of the mother, interdictions that prevent the newborn to become impure), marriage (who chooses the identity of the spouse, who is a suitable spouse, that the bride must be a virgin, where newlyweds will live after the marriage) and death (how the dead should be dressed, the time and duration of mourning, what should be given away for the dead's soul).

Not respecting community traditions and norms, not respecting the authority of the oldest man in the extended family leads to marginalization and to the impure person status. (Grigore D, 2010)

Solidarity inside rroma communities

Traditional rroma communities prefer to be, to the extent to which this is possible, outside state authority. The solidarity within rroma communities has two functions: to protect the community from state interference and to promote a form of traditional, diffuse, collective authority, like the community leader or “bulibasha”.

Communities are well structured. Disagreements are settled by traditional rroma judgment. Bulibasha authority or the authority of the oldest male in the extended family is recognized.

Traditional rroma judgment has no power in the absence of social cohesion without which group renegeation would have no meaning. Social cohesion is based on the functioning of the rroma traditional judgment that limits, as a social control factor, deviations from proper conduct.

Inside rroma communities, social control is carried out by respecting purity and impurity norms that dictate individual behavior and individual relationships. (Nistor D.M, 2011)

For the rroma, the support of the extended family and that of the community is important in case of hospitalization, because it reaffirms their social status:

All of my children! In these matters, if you want to know, we are very united! Even strangers have an obligation! If a stranger does not come, it means he hates us! We stand by each other! How do we come? All of my children... well, my children have their wives, and the men have the women... From the women's side come in-laws, their children, their relatives, so we come from 3-4 families like that! We stick to each other, you know? And when one of us is sick, he must be accompanied... Yes, right. Because if some don't show up... For example, for my daughter in law, her father didn't come, her mother, her brothers... ok, her brother came, but his wife didn't... His

Postmodern Openings

wives' parents must feel that pain... Yes, we have a belief: you must be near that person! **SI.2-i13af2-rr**

The same patient explains:

If we communicate with each other, all of this audience stands still. They go now if my sister's relative has a problem, they will say: look, she did not come! Never mind, we will do the same. And when it's their time, they do not come either. And when we are hurt, they say: When we went to the hospital or to the court house, you didn't come. Why should we? So we keep track of those things. **SI.2-i13af2-rr**

Each of the people that accompany the sick at the hospital expects the same kind of support in return. Inside the chaste, an evidence of these things is kept, as a brush maker tells us:

They come so that nobody from the family of the patient can say: Look, he did not come! Wait, it will be their turn soon. We will do the same! But the patient sees 20-30 people... He is afraid to go to the hospital... He does not need that extra stress! **SI.2-i20am1-bd**

Therefore, family support is important to the patient from a **moral** point of view in the context of hospitalization.

Some of the people who were interviewed acknowledge the fact that the tradition to go to the hospital accompanied by many sets them apart from the general population and may disturb those around them. Still, it is interesting that only the noise factor is acknowledged, not their large number.

It is interesting that the only negative factor recognized is the noise, not the number of the people who accompany the patient:

The family must go! If I have 5 children, we will all go! But we don't make a lot of noise, like others do. We go in an orderly fashion... yes, there's a big difference between us and other gypsies. The language is very different. A Romanian can also understand our language. There are words that we say in Rromani and fit in Romanian language... Other gypsies bring a bad name to our people: look what the gypsies are doing. Our way is to go in an orderly

manner: 60 people, 50 people, in an elegant manner. Their tradition is different. Didn't you see? They pot up tents in the hospital's yard, the police came, they were making a barbecue. That's not the right thing to do... **SI.2-i24am3-ur**

The support of the family is also important while **discussing with the medical personnel**. Many rroma people are not comfortable going to the doctor by themselves. They are accompanied by many people. One who has experience in communication with public authorities will also come along and he will act as a spokesperson. Sometimes, in closed culture communities, discussions are carried out by the community leader. This is highlighted by a 40 year old bucket maker who suffers from diabetes and chronic kidney disease. He remembers finding out about his disease from the community leader who spoke to the doctor:

The doctor... told it to bulibasha. **SI.2-i3pm1-cl**

The extended family

The social life of the rroma is based on a system of community rules that gravitate around the identity model of the traditional culture: the family. The rroma family is extended, has great dimensions. Extended families live in the same neighborhood and make up compact communities. The extended family takes care of all of its members, including newlyweds and their children.

In the traditional rroma family, everyone has his own place, everyone knows and respects his statute and role, knows what is permitted and what is not. Each member's role in the family comes with known obligations and rights that leave no room for doubt and confusion. The individual depends on the family and the family depends on every individual's behavior. That is why in such cultures, based on collectivity needs, each individual acts in a more responsible manner than in modern cultures, since he is not the only one who is responsible for his action, the whole family is. While in modern cultures individual welfare is highlighted, according to which the status of the community may be changed, in traditional cultures the accent is placed on community welfare, for which individual welfare may be ignored. Traditional cultures

Postmodern Openings

refuse to risk an imbalance in the community by permanently intruding in individual lives. (Nistor D.M, 2011)

Respecting family cult, if a member of the family has troubles (financial, divorce, sickness or death), the family tries to offer support:

They did not drift apart! The family can never drift apart!”SI.2-i13af2-rr,... I believe they love each other, especially the brothers. God forbid! So we care about each other and feel each other’s pain... SI.2-i25pf2-cj

The same support for community traditions and unity of the family is highlighted by a 71 year old bear handler, who says that the family should look after a severely ill patient:

Who else, if not the family? In our case... it’s out of the question!! SI.2-i24am3-ur

An important role in the traditional rroma family is played by the old people, the family elders and the community elders. Elders are pillars of the extended family, they hold the highest rank in the traditional rroma community, they are judges or healers. In traditional communities, conflicts are solved within the community, by peace judgment, which is preceded by case debate among relatives. Justice is distributive: both parties are partly right and satisfaction must be granted; since there is no absolute truth, trust and mutual respect are the base of the communication and of the communion. (Grigore D, 2010)

The child feels safe within the community by being part of an extended family with numerous relatives. However the child needs to obey to the rules of the nation. Within the rroma culture there are different methods of helping and taking care of the sick and their relatives in order to help them cope with all the worries. When a patient is hospitalized the family joins the patient at the hospital so that he does not feel lonely, in order to help and support him.

There’s no such thing as one of us. It’s all of us! SI.2-i34af1-cj

The same type of support has been described in other cultures as well (University of Washington Medical Center .Communicating with your

The Rroma Family in the Context of Terminal Illness
Ștefana Maria MOISĂ, Mariana ENACHE, Gabriel ROMAN, Andrada
PÂRVU, Rodica GRAMMA

Somali/Albanian/Chinese/Korean/Latino/Russian/Vietnamese Patient.). In the Somali culture the man represents the head of the family. He is the one who makes the decisions about the family, while the woman is in charge of taking care of the family (<http://depts.washington.edu/pfes/PDFs/SomaliCultureClue.pdf>). In the Albanian culture the parents or the eldest child regardless of its gender, are the ones who have the discussions with the doctor. The decisions are made after all the family members have discussed the issue (<http://depts.washington.edu/pfes/PDFs/AlbanianCultureClue.pdf>). In the Chinese culture the devotion for the family is emphasized. The treatment decisions are also made by the extended family (<http://depts.washington.edu/pfes/PDFs/ChineseCultureClue.pdf>). The same attitude is encountered in the Korean culture. However within the previous culture, the bad news is kept secret from the patient. The same approach that avoids communicating the bad news to the patient is encountered within the Vietnamese communities as well. The family also provides care and support for the sick (<http://depts.washington.edu/pfes/PDFs/VietnameseCultureClue.pdf>). In Latin families the decisions are made by the eldest man whilst the family wants to be informed about the patient's diagnosis and prognosis before the patient itself (<http://depts.washington.edu/pfes/PDFs/LatinoCultureClue.pdf>). In Russian families the decisions can be taken by anyone and there is the same attitude towards the bad news. This attitude promotes the belief that bad news could worsen the patient's condition (<http://depts.washington.edu/pfes/PDFs/RussianCultureClue.pdf>). In a well-balanced Rroma family, the men and women do not compete against each other. They complete each other and consider that the man is the "head" of the family, while the woman represents the "heart" of the family. Both roles are important for the wellbeing of the family. The "head" and the "heart" represent a total, united by devotion and mutual attachment which persists over the years having as a common duty to care to another.

The patient's spouse is the first one to take decisions: "My wife is the one who counts the most!" The spouse has the moral duty to be with the patient until the end. The couple goes together through the suffering

Postmodern Openings

caused by the disease. They also tend to isolate themselves from society and dedicate themselves to each other, given that in such a society, the disease is seen as a disgrace.

A 74 year old woman who has taken care of her dying husband, recalls:

For a sick person the two most important things are: Not to have any pain and to have the support of the family! When I was by his side, my husband was feeling like the entire world was his...When I was leaving, he was yelling after me... **SI.2-i15af3-rr**

The Rroma community is a family in itself. The emphasis is made on the shared responsibility of its members to one another having as common ground the mutual aid.

A 41 year old brush maker expresses his views on the coexistence norms within his community:

While we live in the same community, even if we aren't relatives, we need to behave brotherly to each other. We shouldn't be enemies! **SI.2-i20am1-bd**

The community involvement can be observed when a tragedy occurs in a Roma family. The head of the community (Bulibasa) underlines that the entire community is involved in taking care of the sick people who do not have close relatives.

I went myself... I have sent my neighbors to help the sick person. I have paid for his electricity bill or other small things like this. In our community people gather and help each other. Don't you see? My brother is sick and everybody goes to his place and tries to help with everything. We talk about what should be done. This is how we are... we help each other. **SI.2-i6am2-cl**

A great number of the families included in the survey are facing financial problems, living in poverty. An 80 year old woman who also has financial problems and takes care of her paralyzed daughter tells us about the support she gets from the community:

When I'm home everybody comes and helps by giving (food or clothes). When someone is ill, everybody tries to help somehow. **SI.2-i47af3-cj**

The Rroma Family in the Context of Terminal Illness
Ștefana Maria MOISĂ, Mariana ENACHE, Gabriel ROMAN, Andrada
PÂRVU, Rodica GRAMMA

The support and encouragement from the community were very important for one of the participants of the study who was diagnosed with tumor of nasopharynx with cerebral invasion.

*I was lucky because here, in my village, there are a lot of kind people who help me. When I wasn't sick I have worked for everybody in the village who wanted to hire me... and I took care of their cows and this is how people realized that I am a good person, a reliable person. And now everywhere I go, everybody tells me: Feri, take care of you! You are such a good guy! Now everybody encourages me. And this brings me back to life. And even when I go to the warehouse, everybody stops me and tells me: Be strong! And now I somehow feel stronger and I have more courage... And I believe I got used to the condition I have... **SI.2-i35pm1-cj***

A 64 year old woman who has been taking care of her sick son for the past 10 years tells us how her neighbors changed their behavior and helped her:

*People help me...they feel sorry for me... if they have something that I could use, they give it to me...they help me... I have a neighbor who helped me with everything. For example when I wasn't feeling strong enough to give my son a massage, my neighbor did it for me for at least 2 or 3 months. She helped me a lot! And she even gave us food because we don't have enough money. We are 15 people and we only have my wage, 5 million, to buy stuff... What could you do with so little money? **SI.2-i16pf2-rr***

An Rroma man who takes care of his mother tells us about the help he receives from the community:

*I myself was paralyzed! I also had problems with my back! I fell from 9 meters! And eventually my friends and neighbors helped me out. I needed money and I have received money.... And everybody laughed and thought that I was going to stay paralyzed for my entire life... but now I am well and able to work again! **SI.2-i40am1-cj***

In the context of financial support, some of those interviewed, talk about the support they have received from the religious community, especially those belonging to protestant religious groups:

Postmodern Openings

The treatment is very expensive...But the church paid for some of the drugs. We were lucky that we also had 50% discount because she also has a psychiatric condition... And also the entire prescription had a 50% discount. Our brothers from the church paid for the drugs...Because we don't have this money! **SI.2-i34af1-cj**

In contrast to the above issues, in some Roma communities there is the belief that the disease must be hidden because it represents a disgrace to the sick. This demonstrates an increased degree of inter-cultural variability:

Because here in our village people tend to hide their illnesses, conditions...as if they were ashamed... I don't know why this happens... **SI.2-i35pm1-cj.**

Sometimes patients prefer to hide the disease until the end, for fear of social marginalization:

There are all kinds of people... people who feel sorry for you, people who are mean... people who laugh... Well, rroma are a bit sarcastic... so... what to say?! You might get along better with a Romanian or even a Hungarian... because maybe if you share your sorrow with a Romanian, he wouldn't laugh... but if you say to a gipsy: Oh, I'm sick! Or Oh, I have nothing to eat! He would take pleasure in your suffering or gossip... well, this is the world, there's nothing to do... but I didn't tell them... **SI.2-i33pf2-cj**

Sometimes patients prefer to hide the disease until the end, for fear of social marginalization:

There are all kinds of people... people who feel sorry for you, people who are mean... people who laugh... Well, rroma are a bit sarcastic... so... what to say?! You might get along better with a Romanian or even a Hungarian... because maybe if you share your sorrow with a Romanian, he wouldn't laugh... but if you say to a gipsy: Oh, I'm sick! Or Oh, I have nothing to eat! He would take pleasure in your suffering or gossip... well, this is the world, there's nothing to do... but I didn't tell them... **SI.2-i33pf2-cj**

Conclusions

Our study has shown that in most of the investigated communities, the rroma extended family offers support to its members in any situation. The community itself is a family in which every individual is protected, while the community cult and duty feeling govern community relationships.

Care for the ill is a sacred duty for family members, performed despite financial hardships. When family can no longer offer the necessary support, the patient turns to the community for help.

The support of family and community also manifests in the habit of going to the hospital accompanied by many people that remain near the patient for the whole duration of the hospitalization. Often conversations with the medical personnel are carried out by someone who has experience regarding communication with authorities, like the community leader.

On the other hand, in some communities the concept that disease is a shame persists and illness is hidden by the patient and family. In this context, we can conclude that the family represents a trustworthy help for the rroma patient, but there is a certain degree of cultural variability among Romanian rroma societies.

Acknowledgement

This paper was supported by **”Postdoctoral Studies in Ethics of Health Policies”**, contract identification number: **POSDRU/89/1.5/S/61879**, a project co-financed by the European Social Fund by the Sectorial Operational Program for Human Resources Development 2007 – 2013. Priority Axis ” Education and professional training in support of economic growth and development of the knowledge-based society”. Major field of intervention 1.5 ” Doctoral and postdoctoral programmes in support of research”.

Postmodern Openings

Bibliography:

- Nistor, D.M. Familia Rroma între tradiție și actualitate (Doctoral dissertation abstract),2011. Retrieved from www.unibuc.ro.
- Grigore D. Rromanipen- Foundation of Rroma Identity, 2010. Retrieved from <http://www.scritube.com/sociologie/TRADITII-RRROME52734.php>)
- University of Washington Medical Center . Communicating with your Somali Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/SomaliCultureClue.pdf>)
- University of Washington Medical Center . Communicating with your Albanian Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/AlbanianCultureClue.pdf>
- University of Washington Medical Center . Communicating with your Chinese Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/ChineseCultureClue.pdf>
- University of Washington Medical Center . Communicating with your Korean Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/KoreanCultureClue.pdf>
- University of Washington Medical Center . Communicating with your Latino Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/LatinoCultureClue.pdf>
- University of Washington Medical Center . Communicating with your Russian Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/RussianCultureClue.pdf>
- University of Washington Medical Center . Communicating with your Vietnamese Patient. Retrieved from <http://depts.washington.edu/pfes/PDFs/VietnameseCultureClue.pdf>