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END-OF-LIFE SUFFERING IN A PERSONAL, FAMILY AND SOCIAL CONTEXT IN RROMA COMMUNITIES IN ROMANIA. A QUALITATIVE APPROACH.

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Motto: *With us, it's not one. It's all of us*
(*Rroma terminal patient*)

Abstract

The Rroma population represents the largest minority population in Romania. Published research so far regarding healthcare needs and cultural particularities of this population are scarce and lack continuity. This increases the risk of cultural insensitivity when healthcare is provided to patients who belong to this ethnic minority. At the end of life, psychological and spiritual suffering of the Rroma is polymorphic, and identifying the factors that generate this suffering, linked to the beliefs, traditions and Romani culture, is essential in order to insure optimal support at the end of life to the Rroma patients.

Keywords Suffering, rroma, end of life.

Introduction

The right to a dignified death and personalized access to health services, based on deeply rooted cultural values is recognized all over the world as one of the fundamental human rights. We generally tend to forget that the concept of “natural death” and that of personalized access to health services vary considerably among cultures and even among individuals of the same culture, which may lead to misunderstandings and cultural intolerance. Hence, health services should be provided to the various communities in line with their cultural specificity which the medical staff should be aware of.

Culture is defined as a constellation of shared meanings, values, rituals and interactive patterns that determine the way people see and understand the world. The religious beliefs and practices influence the way people react when dealing with suffering, fear and death, and

provide meaning and support. Moreover, modern medicine is, in itself, a culture, and medical education varies the medical professionals' attitude (Berger, 1998; Kleinman, 1995; Good, 1994).

Culture explains what death is, why it happens and what people must do in order to meet it with integrity and honor; it also explains the way family and community members must support the dying person (Surbone, 2011). Death has different meanings and understandings from culture to culture.

The relation between culture and health or sickness is even more important in the event of a terminal diagnosis, as it may lead to social stigma (Daugherty & Hlubocky, 2008). Contemporary medicine is mostly culturally "reluctant". The main focus is placed on cognitive aspects taken out of context and the identification and treatment of physiopathological aspects, which makes medical professionals fail to identify cultural aspects that determine the emotional and spiritual connections in the context of the cultural values that relate to the disease. During the last years, the accent has been placed on the technical aspects of the medical profession, and even patient communication aspects have been sometimes neglected (Daugherty & Hlubocky, 2008).

Although efforts have been made all over the world for the improvement of end-of-life care, there is evidence that such efforts do not reach those who are at a risk of not benefitting from appropriate medical care: patients belonging to minorities. Additional barriers are cultural intolerance and lack of trust in the health system due to the long history of racism in medicine. These barriers may be: institutional, cultural and individual (Krakauer, Crenner, Fox, 2002).

The Roma population originates in northern India (the Punjab region) and has been known in Europe for almost a thousand years. Among the 7 to 9 million Roma currently living in Europe, most of them live in Central and Eastern Europe, where they stand for approximately 8% of the population in countries such as Bulgaria, Macedonia, Slovakia and Romania (Rechel, Blackburn, Spencer, & Rechel, 2009).

There is little and intermittent research on the health needs of the Roma population published so far. The scarcity of studies on this category increases the risk of lack of cultural awareness in cases where Romanian doctors may be in a position to provide medical care to terminal Roma patients.

This paper aims at providing a deep exploration of the manner a minority in Romania, with cultural characteristics that are highly different from those of the majority population, sees suffering at the end of one's life.

Material and method

This study is a qualitative research that used the research techniques of individual interviews with chronic Roma patients and their caretakers.

The study was conducted in the Roma communities in two regions of Romania – the counties of Cluj (communities of Cluj Napoca, Mera, Bonțida) and Iași (communities of Morilor, Vântu, communities of Dancu, Pietriș-Dolhinești, Zanea-Ciurea, Zmeu-Lungani), where 25, and 23 interviews respectively, were conducted.

The inclusion criteria were:

- persons suffering from severe chronic illnesses;
- caretakers of chronic patients suffering from severe illnesses.

The interviews were conducted in the said communities, at the participants' homes. The researchers' access to the community was made possible by facilitators, leaders of the Roma communities (bulibasha or political representatives), medical associations, general practitioners.

Out of a total number of interviews, 24 were conducted with family members and 24 with patients suffering from severe chronic illnesses. The participants were selected from various groups specific of the region. In the region of Iași interviews were conducted with people belonging to castes of bucket makers, spoon makers, brush makers (closed communities). In the region of Cluj the selected participants came from Hungarian and Romanian Rroma communities in the regions of Cluj-Napoca, Mera and Bontida.

Table 1. Number of participants in the study by the criterion of the group they belong to

Caste	Total number of participants	Women	Men
Region of Iași, closed culture castes: bucket makers, spoon makers, brush makers, bear handlers	16	6	10
Acculturated Rroma in Iași	7	5	2
Hungarian Roma in the region of Cluj	25	15	10

The interviews were recorded, translated and transcribed in Romanian, as part of the interviews done in the county of Cluj was in Hungarian.

The interviews included questions concerning previous experience related to the illness (as a patient or caretaker), specific practices at the end of life, communication of diagnosis and decision making, coping strategies and approach to the terminal disease and death.

The research was approved by the Research Ethics Commission of the “Grigore T. Popa” Medicine and Pharmacy University of Iași.

The participation to the study was voluntary and implied no financial compensation. The participants signed the informed consent sheet before they were applied the research tool and received a copy of the said informed consent. Respondents were given the right to withdraw from the study at any time or to refuse to answer any questions.

The data collected during the interviews were the object of a content phenomenological and thematic analysis.

The limits of this study are represented by the qualitative methodology, which makes the results only valid in the communities where the study took place. The generalization to the whole Rroma community in Romania is not possible.

Results and discussions

Suffering at the end of one's life in a personal context

Psychological and spiritual suffering at the end of one's life comes in many forms and has various causes.

A first psychological sufferance-generating aspect is that fact that, due to the fear of causing pain to the loved ones, patients avoid discussing their discomforting symptoms with them and would rather discuss them *”with my lady doctor...with the lady doctor...that's all...that's all...”* Still, many times the family observes the sick person's condition: *”I'd like a doctor to come and see him 'cause I don't know what to do and he might tell it to the doctor that he is in pain 'cause he doesn't tell me he is in pain. Yes, he tells me not to bother, that I'll get sick myself as I'm really faint hearted ...”*

Another sufferance-generating aspect is the feeling of being a burden to one's family, based on the fact that the patient cannot work and uses the family's low financial resources for medicines: *”So, illness, what can I say, my children and my wife know I need this and that which I don't have, so they shrug their shoulders ...and I must look down again and understand that, if I buy drugs for myself, they do not have any money left for bread ... and if*

I don't take the drugs, then ... well ... but I must think of them too ... and they should think of me... 'cause there are times when we have no money to buy bread and then ...and if I'm sick, then they buy me medicines, but if they can postpone it for a day or two or three, then... let's buy..."

The daughter of a female patient who had a stroke tells us about the guilt that constantly troubles her mother for being a burden to her children: *"Sometimes she feels ... she even confesses it ... she says that maybe things would be better if she weren't around... that she would not be a burden to us...But we answer that it'll go away, we laugh and cheer her up. I don't see things this way because she is my mother and to me she is no burden. Even if she were unable to get out of bed, she'd still be my mother"*.

The psychological suffering is also likely to originate in the patient no longer being the "head of the family" due to the disease, and also to the inferiority feeling caused by the disease.

Within the Roma communities, it is the man's duty to ensure an acceptable economical status for his family, and not being able to do so causes suffering. A 65-year old man suffering from a severe malignant disease shares us the feeling of guilt he has towards the family who take care of him: *"Doctor, it annoys me 'cause even when I eat I ask them: give me that, do that for me! I can't go anywhere! And I often cry because of my disease! I can't work, I only sit around and order them: give me that, do that for me. I'd like to work! On my own!"*

The fear for the uncertain future of the sick person's children is another sufferance-generating aspect: *"I've been thinking and I'm afraid of dying... I have a little boy who is younger...and still in school ... and... it troubles me when I think of him... 'cause – God forbid! - what if I die and I don't know what will happen to this child ..."*

The suffering of the individual in the family context

We are born alone and we die alone. However, what happens in between the two major events of man's life goes beyond loneliness. Man is a social being: he/she is born, lives, evolves and differentiates as a distinct being only in relation to the others.

The Roma's social life is based on a system of community norms and concepts that orbit around the identity pattern of the traditional culture: the family. Family in the traditional Roma culture stands for the fundamental value of solidarity within the community, a factor of social control and ethnical identity preservation. In the traditional Roma culture, everything revolves around the family which is the foremost unit of social organization, an extended system of relations, an economic unit which provides for individual protection, especially in crisis situations: *"Well, who if not the family?! With us, the Rroma... there's no such thing!"*

Maintaining cohesion and family relations are essential in the Roma family. The extended family is far from being a simple reproductive group, the social family relations fulfilling a series of functions that the biological one cannot meet: political authority, economic status, representativity, legal power. The family relations structure the social relations, generating social networks and providing a balance of economic resources and power central factors (Grigore, 2001). The Roma family is actually the community, not only by their social control factors, which are inherent for any traditional society, but, in particular, through the system of cultural relation, which is why we can call it "community family" (Petcut, Grigore & Sandu, 2003)

Thus, if one shows respect to the family cult, one is helped by the family in any situation: financial crisis, divorce, illness or death: *"They haven't drifted away! Family can never drift away!"*; *"... I think they love each other very much, the brothers and sisters especially. God forbid! So, we do care about one another and we suffer for one another ..."*

The suffering of the dying patient is severely sensed by the family who are capable of major sacrifice to make the last days of their sick member more bearable. The family cult and a sense of duty guide the family members' conduct towards the dying patient (Rosenblatt, 1993).

The Roma couple is characterized by mutual devotion and attachment lasting over the years, with an obligation of taking care of each other: *"Well, if my wife were sick in bed, it would be me the one to take care of her ... to clean her, tidy her, feed her... So the spouse ..."; "The wife matters the most! Children are not like the wife ... or the husband. ... Well, that's how things are... So, the wife and husband are more important than the children!"*

We notice a similar situation in a Roma family whose son is diagnosed with epilepsy and severe physical disability and whose parents lovingly take care of him. The 33-year old man tells us: *"I can't go to the toilet if they don't help me 'cause I... my mother has to clean me, take care of me, do everything ... When I was really, really sick, I mean really sick, when the medicine didn't help, I stayed in hospital, and it was my mother who stayed with me, helped me, prepared me, bathed me, she did it all. I cannot help myself; it's only my parents and my brother who can help me."* This situation actually originates in the moral norms that have deep roots in the Roma culture as well, i.e. „the cult of one's children". As a member of the extended family, having plenty of relatives, the child feels protected within the community, but he/she also has to prove he/she respects the norms of his/her community. The child is the "God" of the Roma family, the embodiment of absolute purity, a guarantee of the people's continuity (Grigore, 2001).

To the sick person, being taken care of by the loved ones has a special significance, and it is also perceived as an unwritten obligation of children towards their parents. The community openly blames the cases where the family fails to take appropriate care of its sick member. It induces a feeling of shame and guilt, and the sanction is stigma in the community and social separation, which is an extreme punishment for a Roma.

The family takes care of the dying patient with devotion and thinks it is God's will, it is fate, and a compelling moral obligation. *"Well, if he says he'd like a certain food, we must get it for him 'cause if we don't he cries... He needs it! And we don't have the means to get it; we do everything we can to get it for him."*

The wife of a diabetes patient remembers: *"It was me who injected the insulin to him, I took care of him... when they cut off his leg, I was hospitalized with him everywhere, he also had a stroke, so I took care of everything. I gave the treatment, I fed him ... If it was difficult?! I don't know ... It was the pain like that, temporarily. I saw him in pain, but me, I didn't feel ... how should I put it, helpless. I was grateful that I saw him alive in bed... But him no, he wanted to die. He was never at peace thinking he was sick"*.

Many times the responsibility of the family members of permanently being there for a terminal patient represents a physical and psychological challenge. But the Roma family, due to the inherited education, is always near the dying person, sacrificing personal comfort to this end.

A 74-year old woman who devotedly took care of her dying husband remembers: *"To a sick man both things are important – not to be in pain and to have his family by his side! When he saw me around, it was as if the world was his own... When I was not there, he would call out loud for me..."*

In the Roma culture, there are several ways to help the sick and their close ones. Support alleviates despair and worry and problems become smoother to cope with if thus shared. Hence, when a Roma patient is hospitalized, the family deems it an obligation to be with him/her so as the patient does not feel lonely, to support and help him/her: *"With us, it's not one. It's all of us!"*

In our study, we have encountered situations where relatives wish for their own death, but not for the death of the dying patient. A woman seeing to her sick husband suffering from a severe oncologic disease, exhausted by her husband's suffering and her own difficulties, wishes for her own death that she sees as her own redemption: *"Well, it's God who helps you go to heaven...here it is very difficult, always sick and upset. Every minute I would like to die because things are scarce and it's hard for me with him being sick... I know he won't get well and that upsets me, that I know the truth is he won't cure ..."*

The suffering of the individual in a social context

The educational pattern in the traditional Roma family is based on experience and intuition, the equality of children and adults, and also rendering them responsible in relation to the others – collective responsibility – and the induction of a sense of shame and need of tradition preservation. The community action exerted on the family gets stronger as the boundaries between *family and community* are more flexible, as is the case of the extended family, which has the characteristics of a community itself, where the groups of descendants owe themselves mutual loyalty due to the bilateral relations of complementary filiations and alliance relations: *"Even if we are not close relatives, as long as we live in a community, we need stability and we need to behave like brothers, not be enemies!"*

The Roma perceive illness as a shame, a punishment for the mistakes the sick person has made. This is the reason why the Roma choose to hide health problems from society, which problems are, however, well known by all family members.

Our study has identified two different attitudes of society towards the sick person. On the one hand, the sick person isolates himself/herself at his/her own choice or society members exclude him/her from the community life, sometimes even for a mere remediable vision impairment: *"they don't like to accept the glasses, they say it's a shame, a fear, a handicap: "You're blind. We don't want to deal with you anymore!"*

Patients may even feel stigmatized: *"There are all sorts of people ... some feel pity, some are mean ...some laugh at you ... Well, the Roma are scornful ... They are scornful ... so ... how can I explain?! You'd rather get along with a Romanian ...even a Hungarian ... maybe if you tell your trouble to a Romanian, he won't laugh...but tell it to a gipsy: I'm sick! or I have no food to eat! he is rejoiced by your trouble or gossips... well, this is how people are ...there's nothing you can do ... that's that...but I didn't tell them ..."* or *"People are not like that....No, they aren't ... No....they don't treat you well ...No ... Before my husband got sick, they treated us better ... Indeed... yes!"*

This reaction of rejection has several explanations, among which the fear of coming into contact with the sick so as not to get sick themselves, the wish not to come in contact with those who are inferior, weaker, as getting sick is for the Roma individual a reduction of his/her social status given that the Roma community praises prosperity.

The Roma, being educated in the community cult for centuries, need social integration, and isolation causes sufferance: *"Before I got sick, I used to go to any party, any event in the village! Now, if there's a wedding, I'm no longer invited, if there's a baptizing, I'm no longer invited, no matter the event in the village I am not there... because of this illness and they know this man can't drink, this man can't eat, this man can't have fun, why should he come then? To bring money and that's all? People like that, like more serious people, they don't invite me, but later they come and see me and bring me something, a little bit of food, a glass of juice or a bottle of juice"*.

On the other hand, we deal with completely opposite statements, where patients openly discuss their diseases with their neighbors, having the compassion and support of the community they are part of. *"They keep asking how he is, what he does ... When I meet the neighbors in the village, they ask and say: How is Șandor, is he alright?; "Yes, I was lucky*

that the people in the village have been very good to me!" People would stop me in the street and say: Be strong! Be strong! Don't give up! And after a while I got more courage and somehow I got used to it ..."

Some patients mention the support of their religious community, in particular those that are part of Protestant groups: *"The expenses are very high ... Someone helped us 'cause otherwise we could not have managed on our own! The brothers of the Church paid for it all!"*

Despite the fact that in the Roma community the idea that disease should be a secret still persists as it is a shame of the sick person, we notice that the patient, having reached a state of despair and having no other support, still turns to the community. Sometimes, the sick person, in need of the support of his peers, but understanding that his/her loved ones may suffer when finding out of the severe diagnosis, seek compassion among the community members, admitting to his illness, even if, according to deeply rooted stereotypes, illness means shame: *"When I got home, I told everyone, my family, my neighbors, my colleagues, my friends ... 'cause in our village it is customary to sort of hide your illness. As if it were a shame ... They are ashamed ... I don't know why, I have no idea why... Still, from the very start, I kept it a secret from my old father, I kept hiding it until he understood ... I knew it 'cause he's been crying and he's been upset ever since ..."*

As the community cult is promoted, the community members usually help the ones in crisis. To many Roma, community support is very important and even helps in fighting the disease.

The Roma tradition to go to the hospital accompanied by the entire family is also a manifestation of compassion, care and support for the patient. This action is also projected into the future, because everyone presents is ensured this way that he/she will also receive the same support in a similar situation.

A 66-year old woman explains why so many people come to hospital when a Roma is hospitalized: *"All my children! With us, when it comes to such things, if you want to know, we're united! Even those who are not family have an obligation to come! If one who's not family does not come, it means that person has a grudge against us or hates us! But we are all together there, one next to the other, like that! Yes, it's customary: you must be with that person!"*

Relatives stay with the patient for the whole duration of the hospitalization, and usually someone even spends the night by the patient's bed. He who expresses solidarity this way to the suffering person expects, in his turn, the others' solidarity: *"They come so that no member of the hospitalized patient's family say: Look, that didn't come! Wait and see till it's their turn! We'll do the same! But the sick man sees 20 or 30 people who've come to see him... The patient is afraid to go to hospital... Somehow, he has that fear too!"*

A man of the bucket makers' caste tells us: *"The two of us (husband and wife) went to the hospital...but later all people, all bulibasha rushed to come ...The whole neighborhood came to see us in I!"*

When a person is dying, the Roma come from great distances to say goodbye. The entire (extended) family participates in taking care of the dying relative. At the same time, the relatives are at the patient's side the whole period of time he/she is hospitalized. Usually, there will be someone staying with the patient during the night. Even after the patient's death, a large number of relatives and friends come to the hospital and at the dead man's house to provide moral support to the family.

A deceased patient's wife remembers: *"They did respect him alright, until he was gone, there were people coming from C., T., P., B., everybody was here, there was no room left for more cars. He was respected, I couldn't say otherwise, I thank them all."*

Conclusions

The traditional Roma live in a world dominated by taboos, their own laws and rules that govern and prevail in all aspects of their life. Their community is a static, change-resilient one that preserves magic beliefs and is closed to the influences of the dominating society. Any individual born and raised in such a society should take over and further these beliefs and taboos. To the Roma people, respect for tradition is sacred and unalienable, equal to the value of a dogma.

The suffering of the terminal Roma patients is generated by a series of fears like: causing suffering to the loved ones, placing a burden on the family members, the impossibility to provide for family members caused by the disease and losing the dominant position in the family, but also concern for the fate of those who will have to survive after the death of the sick person.

In the Roma culture, taking care of the sick is a sacred duty. The interviewed patients and their families completely reject the idea of confining the patient to a hospice-type institution as, to the terminally ill person, the care of his/her loved ones bears a special significance.

Illness is perceived as a shame and sometimes is dissimulated from the community until it reaches the final stage. Once the community becomes aware of its members' illnesses, it generally helps those going through crisis, however, the latter sense the discomfort of marginalization, as the healthy members of the community avoid contact with the sick for fear they might get sick themselves.

The dying person's suffering is acutely perceived by the family members who are capable of major sacrifice in order to render the patient's days easier to bear. The family cult and sense of duty guides the conduct of the family towards the terminally ill person. Though they are taken care of with love and devotion, the sick sometimes feel they are a burden to the family. Sometimes, family members feel exhausted and wish their own death, not the sick person's death, as a way to escape suffering.

Based on the findings of our research, we conclude that knowing the Roma behavior and fundamental beliefs is essential for the interaction of the medical professionals with this ethnic group. Cultural mediators can offer a priceless aid in identifying the factors that modulate the attitudes of Roma towards health and the healthcare system, and being aware of these factors may modulate healthcare offered in accordance with the needs of the patients who come from communities that are culturally different from the dominant population.

Identifying the factors that generate psychological and spiritual suffering, closely linked with the beliefs, traditions and Roma culture is essential in order to ensure optimal support at the end of Roma patient's life, both in hospital and in home care, placing the accent on patient dignity.

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