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Intercultural mediation with the roma community in health-care contexts

Mediación intercultural con la comunidad roma en contextos sanitarios

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Abstract

Intercultural mediation essentially deals with perceptions. Perceived reality is frequently very different and far removed from actual reality. From our human and cultural position we must endeavor to understand the «other», starting from the principle that our lives are guided by certain norms and principles that are impregnated with cultural values and traditions. Any attempt to find logical reasons for this perception, in other words, the causes and consequences of the behavior and attitudes of those who do not share our culture, will be in vain and take us nowhere. Only by changing our approach can we achieve the fluency of understanding and comprehension that we all strive for. In sum, we must face up to the difficulties of communication by questioning why reality is perceived in this way. This approach activates our perceptive capacity, facilitates attitudes of comprehension, and stimulates the dialogue and communication on which interculturality is grounded.

Keywords: Gypsies-Roma, intercultural mediation, intercultural communication, social anthropology, racism, exclusion, apartheid, health care institution.

Resumen

La mediación intercultural esencialmente es una cuestión de percepciones. Desde una posición humana y cultural debemos comprender al «otro» partiendo del principio que nuestras vidas están orientadas por normas y principios que están impregnados de valores y tradiciones culturales. Aplicar «nuestra lógica» buscando las causas y las consecuencias del comportamiento y de las actitudes de aquellos que no comparten nuestra cultura es un intento vano que no nos lleva a ningún lado. Sólo cambiando nuestro enfoque podemos lograr el entendimiento fluido y la comprensión que deseamos. En suma, debemos enfrentarnos a las dificultades de comunicación cuestionándonos por qué la realidad es percibida de esta manera. Esta aproximación aumenta nuestra capacidad de percepción, facilita actitudes de comprensión estimulando el diálogo y la comunicación.

Palabras clave: gitanos, mediación intercultural, comunicación intercultural, antropología social, racismo, exclusión, apartheid, instituciones sanitarias.

1. The cultural and socio-medical context of the Roma community

Any analysis of intercultural communication and mediation in health care contexts must start with an understanding of the culture of the group, in this case the Roma community.

The Spanish Roma¹ possess certain cultural traits, traditions and worldviews that are diverse and sometimes very different from those of their surroundings. However they also share with the rest of the Spanish population the embedded culture, values and traditions of the area in which they live, whether it be Seville, Madrid or Valencia; they are just as diverse as the rest of the Spanish population. Failure to understand this situation, based on the age-old miscegenation of Roma groups with their environment, gives rise to certain tensions in intercultural relationships.

From a theoretical perspective, this situation is explained by the Roma groups' century-old shared existence, the intermingling of their life and culture, with that of their socio-cultural environment, which has given rise to a two-way process of enculturation that has enriched the lives of both Roma and Payos.² This cultural mix is seen in numerous examples of the influence Roma culture has had on Spanish culture; it has left a lasting mark on Spanish languages, music, dance and art. The result of this hybridization process is that their identity is just as much Spanish as it is Roma and vice versa.

This construction of the Roma identity, evolved over centuries, has two immediate practical consequences. Firstly, the significant differences between Spanish Roma and other Roma groups; and secondly, in the way they differ from other immigrant groups that have arrived in Spain in recent decades.³

The Roma case presents a paradox within the framework of intercultural mediation as understood from the foreign-indigenous dichotomy.⁴ From the intercultural mediation approach this reality leads to certain confusion, since the starting point

1 The reflections in this paper refer to Spanish Roma. The groups of European Roma, particularly the growing numbers from Romania, Bulgaria, Kosovo and Croatia now living in Spain, are not included since the diversity of situations they present goes far beyond the scope of this analysis and could not be accurately reflected here. It remains simply to note their presence and the fact that they are also affected by difficulties in communication with health care institutions.

2 The term *Payo* is used by the Roma to refer to the non-Roma community. The etymological derivation of *Payo* lies in the word «peasant» and originally distinguished the nomadic life of Roma herdsmen from that of the settled peasant life.

3 One of the factors that must be taken into account in any intercultural mediation with the Roma group and in any context, including the socio-medical context, is the fact that the Roma culture is an indigenous culture with a long tradition of coexistence in the European context. While the presence of Roma groups in Spain is documented in historical records as long ago as the 15th century, many historians argue that their presence may date back even further. This long-standing coexistence with the majority society has generated significant differences from other cultures that have arrived in Spain more recently, and this situation is one of the main threads running through the present reflection on mediation.

4 Spanish Roma cannot be understood within the limited inside-outside dichotomy, as in the case of second-generation immigrants, who are both inside and outside, indigenous and foreign at the same time. Liisa H. Malkki's perspective in «Purity and Exile» makes a vital contribution on this issue.

for mediation is knowledge about the essential features of the culture or cultures for which a point of communication and dialogue must be established. What happens when a culture is perceived not to have any specific, clear and objective differentiating features? What happens when there appears to be an absence of any objective difficulties that hinder dialogue and communication? When problems of linguistic communication, of awareness about health-care resources, of cultural understanding appear to be absent? Where, therefore, do the difficulties lie?

The most commonly heard response is that there is a lack of willingness and predisposition to promote this understanding either on the part of Roma families or on the part of the health care system, depending on the point of view. The consequences of this position are that, in the first place, communication difficulties are accentuated, and tensions and conflicts increase in the shared space of the social relationships in health care contexts. Furthermore, not only is the conflict of communication perceived, but it is also deemed unsolvable because it does not seem to have any reasonable causes.

Intercultural mediation essentially deals with perceptions. Perceived reality is frequently very different and far removed from actual reality. From our human and cultural position we must endeavor to understand the «other», starting from the principle that our lives are guided by certain norms and principles that are impregnated with cultural values and traditions. Any attempt to find logical reasons for this perception, in other words, the causes and consequences of the behavior and attitudes of those who do not share our culture, will be in vain and take us nowhere. Only by changing our approach can we achieve the fluency of understanding and comprehension that we all strive for. In sum, we must face up to the difficulties of communication by questioning why reality is perceived in this way. This approach activates our perceptive capacity, facilitates attitudes of comprehension, and stimulates the dialogue and communication on which interculturality is grounded.

2. Intercultural communication with the Roma community in health-care institutions

Before we turn to specific aspects of intercultural communication between Roma patients and health care personnel in medical institutions, we must briefly examine the political and social position of the Spanish Roma. Although this reality is not directly related to aspects of culture, it does radically influence the intercultural relationships established with Payos, and is therefore important.⁵

⁵ The impact that the historical (since the 15th century) and contemporary persecutions have had on the sociopolitical relationships between Roma and Payos has been dramatic: segregation into ghettos, effective denial of any chance to integrate in the educational and employment systems, rupture of psychosocial links with society and the most dangerous myth of racism has led to a situation in which most Roma assume the role of «society's scum».

Like most conflicts, health care related conflicts particularly affect the most disadvantaged social groups and those with the least resources. These include not only economic, but also personal, professional, and communicative resources. We must therefore focus our attention on this group without ignoring the aforementioned perspective of diversity within the Roma community.

The most disadvantaged Roma groups hold a political position of subordination within society. Their typical profile is one of a family living in a social housing ghetto, on non-contributory welfare benefits, existing on a subsistence economy, and working in temporary or marginalized jobs. Young Roma are often expelled from primary school or have high rates of absenteeism, and they never reach compulsory secondary education. Both adults and young people are functionally illiterate. These are the groups that are not allowed into certain bars or clubs. Property owners do not rent them housing; employers do not give them jobs. This is the image of the Roma family that forms part of the collective stereotype of the Roma community and which is ridiculed in certain television programs with pretensions to «humor». The impression is that all Roma are like this, clearly a huge fallacy that belongs in mythical history. Nonetheless, they do exist.

This political position of segregation takes its toll: the most negative consequences are the communication difficulties with the Roma in many institutions, schools, public administrations, and of course, health services. The most direct consequences of this lack of communication are the mutual defensiveness of the opposing groups, and the arousal of distrust provoked by fear. Attack is seen to be the best defense, leading to aggression and violence: symbolic violence and explicit contempt that may lead to physical violence and threats.

Although I stated above that these Roma groups find themselves in a political position of absolute subordination at ethnic group level, it is perfectly true that in their personal day-to-day interaction, their position is one of protest, if not rebelliousness, and is certainly a long way from submission. Countless statements illustrate this situation, such as the following:

My parents never left me anything, but they gave me the best inheritance. They taught me respect and how to live honorably without putting anybody down, but at the same time, without letting myself be trodden on. I can hold my head up wherever I go because they taught me to be a person and to respect other people. Roma, Payos... everybody. When anybody looks down on me for being a Romni⁶, or when they look at my family or other Roma ... I can tell you that even though I'm nobody special ... I tell them what I think. I've taught my kids to defend themselves against racists without being violent, but to always

⁶ The Roma terms Rom and Romni are used in this paper to refer to a Roma man and a Roma woman, respectively.

be firm... you know? One thing I'm sure about is I'm not going to bow down to that trash!

Romni pharmacy salesperson, 39 years old

This was said by a woman with personal resources whose position is one of openness and dialogue based on respect for the individual. In other cases, much more violent attitudes emerge. Aggression is clearly associated with a lack of personal resources, as in the case of this grandmother whose three-year-old granddaughter was in hospital, and who was unable to control her distress in a very upsetting situation. She expressed herself as follows:

Well I feel much worse pain for my little girl than for her (referring to the accident and emergency nurse). What do you expect! My little girl, poor little thing, with that drip stuck in her, and she says she can't let me in. My poor little angel ... (sobbing). I'd throttle that battle-ax Payo for less!

Romni street vendor, 54 years old.

Significantly, these attitudes reinforce the stereotype of the Roma as an aggressive and violent group. In contrast to some other groups, these experiences are generalized and the violent attitude of one person becomes the violent attitude of «all Roma».

This aspect must be taken very closely into account in cases of mediation. It is essential to adopt preventative measures that encourage the perception of hospitality and acceptance, and that promote a feeling of refuge and protection. There is no better recipe for intercultural mediation with any group, but particularly those such as the Roma who are subject to exclusion and racism from part of society.

Many Roma regard health care institutions as distressing places. They are alien spaces in which everything is different and where the established norms are not only strange, but in many cases are at variance with their own. The most pressing concerns refer to the lack of understanding about the medical process, the absence of freedom to come and go at liberty, together with dependence on the medical staff's decisions and enforced coexistence.

Roma patients frequently come to health care institutions in cases of extreme necessity and driven by symptoms of pain and discomfort. They are places in which the individual and his or her family have no control over their «destiny». Once in hospital, the patient's freedom to leave is limited by criteria set by the medical staff. It is the doctor who takes decisions on how long the patient must remain in hospital, depending on the diagnosis. Our respondents explained this perception as follows:

A hospital is like a prison, like a school, a place where you can go in but you can't get out.

Rom fruit wholesaler, 34 years old.

The perception of distress arises and increases in proportion to the level of understanding about the medical process. The most disadvantaged Roma families suffer particularly in this situation, as a result of their limited basic education and lack of familiarity with medical terminology. This linguistic isolation is one of the aspects that patients and their families highlight most frequently. They speak the same language, but the quality of communication is extremely deficient, if not totally absent. The following statements help to illustrate this point:

It's like, they use such words ... Lord above! No one can understand them. They could explain things in different ways.

Rom street vendor, 52 years old.

Look, I'll tell you something, I've had an education and I still don't understand them. It seems like they're just speaking for themselves. We're human too and they've got to make an effort to explain things; people's lives are at stake here. And if I'm having problems, imagine some poor woman who hasn't got the first idea.

Rom IT worker, 32 years old.

What gets to me most of all is not how they speak to you, it's the way they look at you. The way they look you up and down, it's like they're examining you. There's no trust. From the first moment ... the way they look at you really puts you off. We haven't had much education, but you can tell these things, you can practically read their thoughts, I can smell them ...

Romni housewife, 27 years old

A further notable aspect is the distress caused by dependence on the doctors' or health care personnel's decisions about the patient's food and his or her freedom of movement.

Nobody would touch that food. The soup looked like it was off. So because he didn't eat he got worse every day until my aunt started bringing him soups and stews in from home. The nurses didn't like it, but what were we supposed to do?

Romni sales assistant, 28 years old

At the level of primary health care, relationships with doctors follow a similar pattern to that of the general population, with certain variations depending on the patient's age or level of education. A highly conditioning factor is the socio-affective relationships the doctor or the health care personnel establish with the patient. As for the relationships with the family, doctor are also conditioned by the personal knowledge he or she has of the patients and their families. Notable improvements

can be seen in long-term relationships where personal bonds have been established and the doctor is well acquainted with the family and the health circumstances of the environment. The following statement ratifies this interpretation:

Oh yes, Don Salvador, that doctor was something else. You wouldn't believe what he'd do for us. Day, night... whenever you called him... there he'd be. Always with a pleasant word and some good advice. He was always our family's doctor... all my life... my mother, God rest her soul, my uncles and aunts, all of us. I reckon he just had to look at you and you were cured. I would swear on my life for him, that's how much I cared about him.

Rom street vendor, 82 years old.

The doctor's age is appreciated as a relevant indicator of his or her experience and knowledge, although positive relationships with younger doctors are not uncommon. Regardless of the doctor's age, his or her emotional involvement with the patient, demonstrations of affection, and concern are highly valued.

In my time, good doctors were older mature men, not many were young. Now everything's different. When I was in hospital I had a lacorrilla⁷ looking after me. At first I asked her if she was a nurse because she was so young. She cracked up laughing and thanked me for making her feel younger. She took my hand so gently and she looked after me like nobody had ever done before. She was just a girl, but what a class doctor... it was her that got rid of what I had. In two days I was home, but she didn't leave me for a minute. I am really grateful to her.

Rom scrap dealer, 75 years old.

A doctor who does not establish socio-affective relations in his or her dealings with the patient is regarded negatively, and distant and «professional» attitudes generate lack of confidence and fear. Where this situation arises, the diagnoses given are commonly disregarded and other doctors are consulted for a second opinion. Most respondents highlight the importance of affective communication, as expressed by this elderly woman:

In my family, what you want when you are going through a bad patch (illness, being in hospital) is a word of encouragement, someone who can understand. There are some doctors that you can tell by their eyes, that they're looking at you, they are listening to you, they are concerned. You expect a friendly word, and you want them to tell you how things are going ...bad ...or good ... but there are others that have such an attitude, you know, they should be thrown

⁷ The term «lacorrilla» defines a Payo woman but has a positive, affectionate meaning. The word comes from the Calo *lacrí* and the Romani *rakli*, with the Spanish article suffix.

in the river for the way they bad feeling they give you. They don't look you in the eye, they don't ask you anything, they don't tell you anything, they are worse than the civil guard.

Romni housewife, 73 years old.

The family doctor or health center is only visited when symptoms of discomfort or pain appear; preventative attitudes such as blood tests or periodic checkups are very infrequent. This situation leads to major problems, particularly in the case of asymptomatic conditions, where the patient is at significantly greater risk.

The concept of illness is linked to negative symptoms such as discomfort and pain. Patients frequently self-medicate in mild cases, and the women of the family will administer paracetamol, decongestants, cough mixture and even antibiotics. If the symptoms persist, then they turn to the family doctor or health center for help.

Particularly significant are «silent» illnesses such as diabetes, and cholesterol or heart conditions that require a controlled diet and physical exercise. The highest rates of disregard for medical advice are seen in these cases. Patients do not understand the concept of serious risk, which they associate with pain or physical discomfort. The main factors behind this attitude are lack of knowledge, and the absence of any perception of the causal relationship between the failure to follow medical advice and the worsening of the condition; the consequences of this attitude are seen repeatedly.

Frequent accounts by both men and women illustrate the lack of awareness about the dangers of this type of condition and the need to acquaint patients with these risks. Many respondents highlight the lack of a controlled diet among this type of patient, as in the case of this woman who is aware of the dangers of diabetes:

Morena? You're asking me about Morena? Well look at her, there she is. She gets worse every day. The doctor told her that if she didn't control her sugar levels, her foot would just get worse and worse. First her toe was bad, and she went to get it dressed every day. Then she got gangrene and she had to have her leg amputated. So there she is, half blind and one leg missing, she's as stubborn as a mule, she just wouldn't stop eating.

Romni housewife, 48 years old.

Given these conditions, it is crucial that medical staff make repeated efforts to familiarize families with the dangers of asymptomatic illnesses and the importance of diet and physical exercise. In general, the Roma community is not conscious of the importance of physical exercise and its benefits for health. Many Roma would identify with this young woman, herself no sportswoman, who mockingly explains:

When I see them Payos running up the hills, sweating like pigs in their flash running shoes, well ... that's ridiculous! You'd never see a Roma running like that ... it's a Payo thing!

Romni housewife, 14 years old.

These experiences are repeated with regard to the controversial issue of essential illness-related diets, or when doctors tell patients to give up smoking or alcohol. The rejection of this type of advice is generalized and is more pronounced in older generations. This situation is partly explained by the serious deprivation Roma families experienced in the post-war period, similarly to many other Spanish families at that time. Many elderly Roma react stubbornly, as illustrated by the tone of desperation in this daughter's description of her father's case:

You already know this. He had an attack (cerebral infarction) because he wouldn't stop eating and drinking. Always a glass of something. And his fatty bacon snacks in the middle of the morning. The doctor told him straight. And he understood perfectly. Imagine. He knew he was going to die but he didn't care. When I said anything, he would curse and call me all everything under the sun... What was I supposed to do? He was brutally killing himself, he would say: "that Payo wants to starve me to death, but if I can't eat or drink or do anything, I don't want to live like that". Then he got better. He was really ill. But he recovered. And here we are again, with the same arguments about food. Always the same.

Romni intercultural mediator, 38 years old.

Another elderly man bemoans his bad luck and tries to justify his uncontrollable passion for food:

The Payos didn't kill me in the war and now this jambo (Payo doctor) is making my life a misery. He's out for my blood, I'm telling you. He wants me to eat like a sparrow. Well, I'll tell you something. A doctor tells a Payo not to eat. And he doesn't eat. But we Roma don't. It's not that we don't want to, but for the love of God we can't. Put a plate of fennel stew in front of a Rom and tell him not to eat it ... and he'll tell you he'll eat it even if he means he's going to die. That's the truth, my lad, you die but with a full stomach

Rom horse dealer, 82 years old.

The elderly —particularly elderly women— with chronic illnesses for which they take medicines over many years, do not differ from the rest of the Spanish population in their use of health centers, which become a meeting place for chatting with other patients, and the doctors appointment is more of a social than a medical ritual.

This situation is most clearly evident in the “repeat prescriptions” process. The following comments come from a frequent user of the health center:

There’s no cure for what I’ve got. I’ve had it for so many years now. But I get on well with the doctors. I often spend the morning in the waiting room with the lacorrillas and we sit and chat about everything. My doctor is a good-looking young Payo and he says: in the end you’re going to know more about medicines than me! God knows he treats me well.

Romni housewife, 84 years old.

It is practically impossible to reliably estimate the number of Roma families who use only private health services; most use a combination of both private and public systems. They attend private doctors and centers almost always as a second choice, but also as a first option particularly in the case of pediatrics.

Private medicine is used by sectors of the Roma community who, in spite of being covered by the Social Security system, also take out private insurance, and also by Social Security patients seeking a second opinion from a private doctor in serious cases. Families who have experienced communication difficulties or who do not trust the public sector doctors they have seen will also use the private system.

Families in better financial circumstances, even though they are covered by the public health system, use the private sector during pregnancy and birth, and also for pediatric care. Babies are given a high priority and the need to safeguard their health leads families to seek appointments with private doctors, particularly those they trust and with whom they feel confident. This context clearly illustrates how socio-affective relationships and personal links with the pediatrician are key elements in this relationship.

On the issue of baby care, cultural factors can arise that at times go against standard medical guidance. Roma mothers and grandmothers have a great store of knowledge about traditional medicine that is passed down from mothers to daughters. In some cases, traditional wisdom such as the importance of long-term breastfeeding (up to 1 year or more) coincides with pediatric advice, but in others, such as babies sleeping with their parents, traditional custom goes against medical recommendations and in these cases families are more likely to follow their traditional ways. Traditional knowledge concerns breastfeeding, diet, teething and sleeping habits. If the baby suffers any kind of discomfort, or if his or her condition involves even the slightest risk, the pediatrician’s advice is followed to the letter and traditional home remedies or natural medicines are categorically abandoned.

Many families visit private pediatricians for reasons of confidence and trust in their diagnosis. Statements in this vein are numerous, such as the following from a mother whose two-year-old daughter was admitted to a public hospital:

I don't like the way they treat her. Do you think for one minute her bronchitis is going to get better with Apiretal? Nobody tells you anything here; we've been in here almost two days and three different doctors have seen her and they haven't said anything to me. They aren't giving her any treatment. Only the masks. Her temperature isn't going down and they haven't given me anything. If Gonzalez (the private pediatrician) was here, this wouldn't have happened. But at this time of year (Christmas holidays) he's on holiday, and here nobody gives you any explanations. He's the type of doctor who makes you feel at ease, every time he's seen my boy he's got it right first time and he's better in no time. I'm desperate, this is a disaster ... (with tears in her eyes) she's not well, she's not well.

Romni administrative worker, 28 years old.

These situations create a lack of confidence among families with babies and in many cases lead to tension between health staff and families, which not infrequently turn into aggressive and violent incidents. Desperation and impotence are the main motives for these reactions. Particularly, when they have children or babies in hospital, Roma families are much more likely to manifest an active, demanding attitude, a far cry from other cultural patterns that encourage submissive attitudes to the hospital system. This attitude may lead to aggressive demands when it is not addressed. Logically, the degree of tension is related to the seriousness of the patient's condition, but the doctors' and health care workers' attitudes also have a major influence. Once again, socio-affective ties, empathy, and communication with the families emerge as key factors in the avoidance of conflict. Sincere concern, a warm, caring tone of voice, and emotional proximity to the family members are crucial factors.

While personal and affective links are important in the doctor-patient relationship, one element of Roma culture, perceptions of pollution, must also be taken into consideration since it can have major consequences in the patient's recovery process.

In contrast to the widespread prejudice about the «dirtiness» of the Roma, frequently associated with garbage, filth, mange and lice, most of the Roma community follow a series of personal and domestic hygiene practices that in many ways have a ritual character and a deeply rooted cultural history. The following statements illustrate these issues within the domestic sphere:

My mother found a Payo woman to clean the house. You can imagine with four men at home and only her to do everything, poor thing she couldn't manage. But I've told her not to let her go near the kitchen. I take care of everything in the kitchen, the pots and pans and everything. I've told her not to let her in there. In my house we've always eaten what our mother's cooked with her own hands and I don't want any stranger touching the things. Imagine how disgusting, yeuch!»

Rom translator, 39 years old.

There is nobody more scrupulous than the Roma. We're fussy about everything. We only eat at home and with the family and if we go out (bars, cafes etc) you have to know they keep the place clean, that you can trust them.

Rommi fruit seller, 60 years old.

These perceptions of pollution in food have significant consequences for patients in hospital, and logically lead to tensions and communication problems between Roma patients and health staff. The following statements throw some light on the situation:

My father. Do you know what he did? Well, he was a fortnight in hospital and he came out worse than when he went in. He didn't want to touch a thing in two weeks. Everything they put in front of him turned his stomach and we couldn't get him to eat anything. You know what it's like, he was sickened by it and he wouldn't touch it ... that's how he was.

Rommi street vendor, 43 years old.

First of all I can't stand being shut in. In a room you have to share with another jambo (Payo) sleeping there. And there he was, doing what he had to do. Smells and everything. I don't have much stomach for eating. And the stuff they give you, those food smells, it's junk.

Rom bricklayer, 34 years old

While this feeling of disgust for the hospital food among Roma patients is something they find practically impossible to overcome, the attitude of the health care staff on this issue is antagonistic.

The food we provide here is very healthy and balanced... All patients are given a diet suited to their needs. They all have to eat what they are given. We can't allow what a lot of them (Roma) want, which is to have food brought in from home. They don't understand that an unsuitable diet might be harmful... to tell the truth it's a constant battle.

Public hospital nurse, 45 years old.

But when faced with the refusal of their sick relatives to eat the hospital food, many families bring food in from home which, as noted above, is against hospital rules. Consequently, this clandestine trafficking of food is commonplace and causes tension:

When I went in to have my baby, the jambas didn't want me to have anything to eat. I was starving, you couldn't imagine how. I only wanted to eat. So I told my family to bring me chocolate and cakes and things from the bakery. The nurse caught me eating a croissant ... and she gave me a real telling off.

Then afterwards when my doctor came, he read the riot act. Everything had gone really well and he got angry with them because they hadn't given me anything to eat.

Romni social worker, 32 years old.

Hospital regulations are necessarily rigid, essentially because they are designed to ensure that patients are following the correct diet, which would be impossible to guarantee without this strict control; however this does not calm the distress and anxiety of Roma patients who feel obliged to eat food they consider to be «polluted». Promotion of communication between health workers and patients on these issues is essential if the atmosphere in hospitals is to improve.

But visits from relations and close friends of the Roma patient are what most affect social relationships in hospital. Depending on the age, the family, and the seriousness of the illness, the patient's family, friends and acquaintances will visit the patient in numbers and with an intensity that is not frequently seen in other cultures. Neither are these visits restricted to one hour; rather friends, relations and particularly close family will remain in the hospital day and night. This family presence in the hospital is continual and can go on for weeks.

The way Roma families cope with hospitalization, a round-the-clock presence during which the patient is not left alone for a minute, is deeply rooted in the community. Relatives and neighbors will stay as close as they can to the patient, ideally in the patient's room, but if not, in the waiting rooms or corridors. Numerous statements referring to these situations were gathered and they appear in all the groups interviewed, as in the case of the following respondent who highlights the positive aspects of this attitude as compared to that of the Payos:

We always have someone close by in the hospital and we stay there with him. We don't leave him for a minute, keeping him company and making sure he feels loved. Everyone stays in the hospital: family, friends, neighbors, people you know... everybody goes to see him. His closest family stay day and night and don't leave his side. The others will come to spend the afternoon or the morning. It's very sad not to have anyone and to be left all alone in these situations; we don't do like the Payos who just leave their people in hospital and that's that. For us it's a custom and a duty that everybody respects. That respect hasn't been lost.

Romni housewife, 36 years old.

These situations lead to tensions and conflicts with the hospital staff. In addition to the problems caused by large numbers of people crowding into the room, the

waiting rooms or the corridors, the medical and health care personnel in general do not understand this behavior. The following statements suggest factors to analyze this conflict:

Really they do nothing in the hospital. They stop us from attending to the patients as we should. Is it normal to have five people around the bed? Well no it isn't. It's just not reasonable to take over the waiting room and wander around the corridors. The patient needs peace and quiet and not an invasion of visitors who don't help him in the slightest.

Nurse, internal medicine ward, 39 years old.

The prejudices and negative images about the Roma are also present in the hospital context, prejudices that are often shared by health workers. Statements evidencing these prejudices are frequently repeated and, in common with the rest of society, they center on the link between the Roma and stealing, dirt and in general, antisocial «wild» behavior.

Do you know what they did in the (hospital) room? They spent their time stealing everything they could; slippers, towels ... everything they could.

Female nurse, 53 years old.

They (the Roma) scare me stiff; I'm not just scared, I'm practically terrified.

Female nurse, 53 years old

In this context, arrangements such as assigning two Roma women to the same room on labor wards can be understood. It may appear to be coincidental, but the Roma mothers are very much aware of the situation, as indicated in their statements:

When I gave birth I was put in a room with Polainas's daughter. Can you imagine? I've never felt so sick in my life. The two of us there in the room with the babies. That room stank of dogs. But they always do the same to us, they always put us together in the same room.

Romni domestic worker and cleaner, 34 years old.

As in other areas of social relationships, Roma who «don't look Roma» because of their features or the color of their hair, are not subject to these segregation processes, as indicated by this blonde woman who told me, with a smile:

Yes, yes it's true, though you won't believe it. Every time a Romni comes in to have her baby they put her in a room with another Romni. But that didn't happen to me and my baby because I'm blonde and they didn't realize I was

a Romni and they put me in with a really friendly lacorrilla. The two of us got on really well.

Romni housewife, 31 years old

Putting Roma mothers together in the same room is probably the result of a strategy designed to avoid problems with Payo patients. However, as the above accounts illustrate, this strategy is doomed to failure because of the wide diversity of Roma families, which means that problems of social relations may still arise. This strategy is based on a deeply rooted prejudice that considers the Roma to be a homogenous group when the opposite is demonstrated on a daily basis. The old tactic of segregation does not resolve conflicts in the slightest; it only serves to aggravate them.

3. Analysis of a case of conflictive interaction

This case was recounted in a session between health workers and Roma women held as part of a training course. One of the nurses present began to talk about the case as follows:⁸

Nurse: One of the nights I was on duty in intensive care there was a traffic accident. The family came into A&E and the husband was seriously hurt and taken into intensive care. As soon as he came in the doctors said he was in a bad way. It was a Roma family. From the first moment the relatives were told, they started to arrive in increasing numbers. After a few hours there were more than 200 people in the waiting rooms and corridors. They just kept arriving. The doctor explained that they could do nothing there and they couldn't be with him and they would be told the minute his condition changed. But nobody moved. The hours went past and they were all crowded onto the ward waiting in the corridors, walking up and down ... you could hear shouting and people crying. There were whole families, men, women and children of all ages... how can they bring their children into that situation?

They kept coming up to intensive care and ringing the bell. We went out to explain that the doctor had already said that there was no change and if there was, the doctor would tell them. Half an hour later the bell would ring again and the same thing would happen.

They were making a nuisance of themselves to everybody, ringing the bell, but they took no notice. After a while ... it would ring again. That's what it was like all through the night.

Romni: (in a low voice to another participant): That was my father-in-law.

Participant: (in a low voice) Tell her he was your father-in-law.

⁸ Although these accounts are in quote marks to highlight the speech of the participants in the interaction, this is not an exact transcription, as the session was not recorded. The discourse was transcribed from notes taken during the meeting and reflects as faithfully as possible the way events unfolded.

Romni: (in a low voice) No, I don't want to say.

Romni: That man was my father-in-law. All their family was in Mallorca and when they found out about the accident, everyone that could come got on planes and flew to Valencia and then from Valencia they came in taxis to the hospital. They all came because the doctors said he was dying and he might not make it through the night. All the family came from Mallorca and everyone from Castellón too of course. The ones from Mallorca brought their children because they came straight from the airport. They couldn't do anything else. They thought he was dying.

Nurse: I can understand the situation but that doesn't justify their making a nuisance of themselves in intensive care all night ringing the bell. There are seriously ill people there who need to rest and the rules are the same for everybody. And what's more we couldn't give them any more information.

Romni: The only thing they wanted was to know how he was. They were very anxious, they couldn't be with him and they only wanted to know if anything had changed. It's true there were a lot of people there. Until they closed the ward so there wouldn't be so much commotion.

In dramatic situations like this, the potential for tension and conflict to reach certain levels of violence is greater. Most of the Roma community experiences death as a dramatic event, particularly in tragic circumstances such as this one.

Grief for the death of a loved one is expressed intensely, a cultural trait that sets the Roma community apart from most of Spanish society, which encourages and values emotional self-control and fortitude in the face of death. Strength is expressed by controlling the feelings and emotions of grief. In the Roma context death is not met with resignation and integrity, but rather with rebellion and impotence.

Death brings together all the immediate and extended family in an act of solidarity and as an expression of the emotional and structural turmoil involved. In the case of this accident, the patient recovered successfully from his injuries.

In these dramatic situations the position of the mediator is particularly complicated. Valid interlocutors belonging to the family must be chosen in order to avoid situations of tension and conflict. Emotional tension runs high and is difficult to control in a large group of people. The key guidelines in these circumstances are: to make positive contact with interlocutors; to achieve a calm atmosphere by locating family members in different areas to avoid crowding; to improve conditions of comfort; and to negotiate with the family on questions such as silence, order in the entrances and exits, and in communication with health care workers. It is essential to act immediately to prevent emotional tensions from overflowing and to negotiate with health personnel on guidelines for the relationship and for obtaining information.

4. Conclusions and reflections on mediation with the Roma community

In general, all accounts given by Roma patients in health centers or hospitals appear to indicate that the difficulties in communication, tensions, and situations of symbolic or physical violence arise as a result of prejudices and mutual stereotypes, and to a lesser degree from tensions stemming from differences in or antagonism toward values, customs or worldviews.

How Roma patients and hospital personnel perceive each other is a highly significant issue. Antagonism arises on both sides. Both groups believe that the «other» is polluted, dirty, has no feelings, is rigid and inflexible, is wild, antisocial and disrespectful, is incapable of respecting norms, is dangerous and evil, and cannot be trusted. The effect of these perceptions is mutual rejection, exclusion, segregation and violence. The health system is part of society and is a microcosm in which the types of relationships occurring in the social system are reproduced on a smaller scale.

The two preceding paragraphs tell of *one Roma reality* but not *the Roma reality*, which is much more complex. At the beginning of this paper I cautioned on the profound differences and great diversity of this group, which from the outside is seen as a homogeneous unit. This is a fact, and my caution is no arbitrary whim. If this fact is not taken into account, this discourse may be used to construct new prejudices or to consolidate already existing ones. My objective is precisely the opposite: to encourage dialogue and understanding by helping to comprehend and not judge certain situations that, because they are not familiar to us, we find strange.

Within this structural framework, but from a macro perspective, the complexity of the many factors that interact in the construction of relationships between the Roma and the health system are not perceived. The macro perspective does not allow us to appreciate the importance of the variations and diversity within the Roma community and their values and attitudes to intercultural relationships.

It is impossible in these few pages to cover the wide range of specific guidelines that help to facilitate communication with Roma families in health care contexts. However, I believe the following aspects are essential key issues in the task of mediation:

- Promote socio-affective links.
- Build up a role of affective authority.
- Reach agreements about who should be involved in communication and the right time for it.
- Select the most suitable interlocutors.
- Give clear, specific information and check it has been correctly received.
- Be aware of the discourse and information used.
- Transmit dignity and respect.

- Help to control passionate and emotional reactions.
- Foster coexistence and integration.
- Be aware of prejudices and stereotypes.

The key guidelines in the question of health care for Roma patients are grounded in the avoidance of prejudices and stereotypes, and in promoting relationships of trust and mutual respect. For the most disadvantaged Roma group, positive attitudes are interpreted in the non-verbal communication of the interaction. They find it difficult to interpret technical explanations, but they are very sensitive to the way others look at them, to gestures of proximity, and to the tone of voice used. It is essential to maintain a firm attitude of authority without sacrificing emotional proximity and empathy. Achieving the balance between these two points must be a priority. An excessively authoritarian attitude will trigger their rejection mechanism and lead to aggressiveness, and on the other hand an excessively affectionate attitude may be interpreted as fickleness or generate lack of confidence. A firm attitude is highly valued as long as it is accompanied by arguments to explain the reasons for any decisions taken and is associated with an attitude of respect and proximity. In sum, the final goal is to construct a role of affective authority.

A further key question is control of what is said and the information given. This group places great value on «the word». Giving one's word is not only a formal commitment but can also be information or a diagnosis. Whether a person's word is kept depends on the personal and professional evaluation of the interlocutor. It is therefore very important to be sure information has been given clearly and specifically, with subsequent verification that it has been correctly received. Any communication should not be taken for granted and *a priori* awareness of the difficulties that may emerge is crucial.

These key factors have a common principle in that the conscience of the interlocutor, the function of intercultural mediation, is to facilitate communication between people with different worldviews. In addition, as in the case of the Roma, they occupy socio-political positions characterized by marginalization and exclusion, the consequences of which are felt in most social circumstances. The health care context is a particularly sensitive environment for communication, and for human social relationships it is a forced meeting place where clashes can sometimes occur. Patience and empathy, sensitivity and respect, tenderness and understanding are absolutely useless if we do not make a profound intellectual effort to understand that the Roma people live in "another world" and for whom communication, rather than an issue they have surmounted, is a real personal and professional challenge for both them and all health-care personnel.

5. References

- CÁTEDRA TOMÁS, María (1976): *Notas sobre la envidia: los «ojos malos» entre los «Vaqueiros de Alzada»*. En: *Temas de Antropología Española*. Madrid: Akal.
- (1986): «Bendito y maldito. Categorías de clasificación...». *Cuadernos del Norte: Revista Cultural de la Caja de Ahorros de Asturias*. vol. 7(1986), núm.35, pp.70-85.
- DOUGLAS, Mary (2007): *Pureza y peligro. Un análisis de los conceptos de contaminación y tabú*. Buenos Aires: Nueva visión.
- GIMÉNEZ ADELANTADO, Ana (2000): «Parole aux femmes rommi» [on line]. En: Roms, Sintés, Kalés- Tsiganes en Europe- Promouvoir la Santé et les Droits d'une Minorité en Détresse. París: Médecins du Monde, 2000.
- <http://www.medecinsdumonde.org/publications/rapports/rroms_colloque2000/publication_view> [Consulta: enero 2007]
- MALKKI, Liisa H. (1995): *Purity and exile*. Chicago: University of Chicago Press.
- SAN ROMÁN, Teresa (1990 a): «Las esclusas de la marginación». *RTS. Revista de Trabajo Social* (1990), núm. 117, pp. 21-33.
- (1990 b): *Vejez y cultura: hacia los límites del sistema*. Barcelona: Fundació Caixa de Pensions.
- (1998): «Las bases del racismo y de la Filantropía». En: *Los valores y la didáctica de las ciencias sociales. Actas del IX Simposium de Didáctica de las Ciencias Sociales*. Lleida: Edicions de la Universitat de Lleida, pp. 75-90. ISBN: 84-89727-73-2.
- (2000): «El mundo que compartimos, nuevas alternativas». *Revista de Antropología Social* (2000), núm. 9, pp. 193-197.